

# Forgotten in a Crisis

Addressing Dementia in Humanitarian Response



Global Alzheimer's and  
Dementia Action Alliance



Alzheimer's Disease  
International



Alzheimer's  
Pakistan

## About the authors

For this report, the Global Alzheimer's & Dementia Action Alliance, Alzheimer's Disease International and Alzheimer's Pakistan have worked in partnership, investigating ways humanitarian emergency responses can protect and support people living with dementia.

The Global Alzheimer's & Dementia Action Alliance (GADAA) is an international network of civil society organisations championing global action on dementia. The GADAA network connects a broad spectrum of INGOs including international development organisations, gender-equality groups, health-focused NGOs and disability rights champions. Demonstrating how dementia intersects other civil society agendas such as development, human rights, disability, older people, women, health, and humanitarian. Alzheimer's Society, Alzheimer's Disease International, Age International and Dementia Alliance International form the GADAA Steering Committee.

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations around the world, in official relations with the World Health Organization. Each member is the Alzheimer association in their country who support people living with dementia and their families.

Alzheimer's Pakistan is the national organisation of Alzheimer's and related dementias. The main objective of this non-government community organisation is to work towards the welfare of people living with dementia and their care givers.

The authors are grateful for additional content, guidance and peer review support provided by network members and leading humanitarian organisations working on intersecting issues.

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**Acknowledgments:** Many thanks to the following people for their invaluable contributions and advice throughout the research process:

Vivvet and Herman Cramer; Constantia and Gale Hodge; and Milagros Negrón. **Alzheimer's Disease International** – Paola Barbarino, Annie Bliss and Chris Lynch; **Alzheimer's Pakistan** – Dr Hussain Jafri and Dr Yasmin Rashid; **Age International** – Chris Roles and Poppy Walton; **Asociación Alzheimer Y Desórdenes Relacionados de Puerto Rico** – Ana L Gratacos; **Alzheimer's Society** – Clara Fiti and Tatjana Trposka; **CBM** – Julian Eaton; **Chatham House** – Rachel Thompson; **Dementia Alliance International** – Kate Swaffer; **Cromance Foto** – Isaak González; **HelpAge International** – Patricia Conboy, Dr Juma Khudonazarov, Verity McGivern and Ben Small; **Hong Kong Red Cross** – Eliza Yee Lai Cheung; **Humanity & Inclusion** – Jazz Shaban; **Human Rights Watch** – Bethany Brown; **Global Brain Health Institute** – Victor Valcour; **Iran Alzheimer Association** – Faraneh Farin; **Llanos Tunas Community Association in Puerto Rico** – Mayris Noemi Ruiz Olmos; **International Federation of Red Cross Red Crescent Societies** – Sarah Harrison;

**International Rescue Committee** – Lilian Kiapi and Gemma Lyons; **Inter-Agency Standing Committee** – Dr Anita Marini (Consultant); **NCD Alliance** – Jessica Beagley and Katie Cooper (consultant); **Geneva NGO Committee on Ageing** – Silvia Perel-Levin; **Puerto Rico House of Representatives** – Luis Vega Ramos; **St Maarten Alzheimer Association** – Dr Raymond Jessurun; **The Guardian** – Amanda Holpuch; **Tokyo Metropolitan Institute of Gerontology** – Dr Shuichi Awata; **United Nations High Commissioner for Refugees** – Vincent Kahi and Peter Ventevogel; **University of California** – Dr Tala Al-Rousan; **World Health Organization** – Dr Katrin Seeher and Dr Fahmy Hanna; **United Kingdom Department of Health and Social Care** – Dilbinder Dhillon; **World Hospice and Palliative Care Alliance** – Stephen Connor.

Views expressed in this report are not necessarily those of GADAA member organisations.

**Design:** Baker Vale

**Front cover image:** Dr Yasmin Rashid conducting a medical clinic for people with dementia in a camp during 2010 floods. (© Hussain Jafri)

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Published: May, 2019

## Methodology & limitations

This report contributes to a growing body of work addressing disability in humanitarian settings. In this report, the first to specifically address dementia in humanitarian settings, we seek to address the initial impact of an emergency on the lives of people living with dementia and the role actors play in the humanitarian setting. This report draws on the results of a systematic desk-based literature review of a broad range of databases alongside relevant research and policy analysis conducted by humanitarian and civil society organisations.

This research does not attempt to be a comprehensive overview of peoples' experiences of living with dementia or wider cognitive or psychosocial disabilities during a humanitarian response. We are limited by a lack of comprehensive data collection and by poor awareness and capacity within the humanitarian sector to identify a broad range of first-hand testimony. These factors in themselves demonstrate the need for greater awareness and action on the issue.

# Foreword



Worldwide, around 50 million people live with dementia. Of these 60 per cent live in low- and middle-income countries, where barriers such as stigma and poor access to social and health care systems present issues even at times of peace. Indeed, this very stigma leads to people with dementia often living hidden from society and

at times of natural disasters, this can lead to neglect, lack of awareness of their special needs for support and ultimately putting their lives at risk.

A great proportion of humanitarian emergencies happen in countries which are already ill-prepared to support people living with dementia. Too often these countries already fail to provide the diagnosis, care and support needed.

The World Health Organization (WHO)'s Global action plan on the Public Health Response to Dementia 2017–2025 was unanimously adopted by WHO Member States two years ago. Contained in the Plan was a commitment to planning for humanitarian emergencies which considered individual support for people with dementia and community psychosocial support. The 194 countries signed up to the Global plan must work with the humanitarian system to ensure they fulfil their promises, but alas! There is little sign that this is occurring on the ground and this is why this report is so timely.

It has been heart-breaking to learn of the experiences of people living with dementia in times of humanitarian crisis from national Alzheimer associations worldwide and through the production of this report. It has also been eye-opening to understand the current deficit in response.

What this report has shown is that there are tools out there, such as the WHO's mhGAP Intervention Guide and Training Manual and the Washington Group Extended Set of Questions, but these are not being used enough – if at all. It has also highlighted the lack of standardisation and a unified approach to supporting people with dementia in crises. Humanitarian actors are not deliberately overlooking the needs of people living with dementia, but they do need support to understand what those needs are. This report aims to provide or enhance that understanding.

I would like to draw your attention to this quote from the report as it really explains why we need to do more and we need to do more now.

*When UNHCR piloted the Washington Group Questions in 98 registration interviews for new entry of Syrian refugees in Jordan, the percentage of people identified as having disabilities increased 25% from 2.36% to more than 27.55%.<sup>1</sup> UNHCR registration staff reported that the Washington Group Questions were useful in identifying 'hidden' disabilities – those that are not visible to the eye or self-reported by the interviewee. Moreover, the neutrality of the questions, and in particular avoidance of negatively-loaded terms, was also said to be useful to encourage disclosure of disabilities.*

Also, the report points out that, people living with dementia and their families are not being involved in the process of planning for policies to respond to crises. This is a mistake; we need to build dementia awareness into planning and implementation of humanitarian response.

This report comes at a time of growing recognition of the need for inclusive humanitarian action. The current lack of inclusion for people living with disability (including those with cognitive and psychosocial disabilities) in humanitarian response is beginning to be acknowledged. Similarly, the specific needs of older persons, the population group most likely to experience dementia, are being noted.

People living with dementia are undoubtedly an at-risk population so the duty of care on humanitarian actors to support their needs is higher – as it is with pregnant women and children under five. Possibly what is not yet fully acknowledged is the scale of the issue.

To those that may require more evidence of the emergency that is dementia nowadays, I would like to remind them of the 52 million people that are estimated to live with dementia right now. As the report states so eloquently, in any given emergency, the burden of proof should not be about identifying cases of dementia to demonstrate a need for action, but to assume that this population exists.

Dementia is ignored at times of stability, so governments and humanitarian actors need to do more during crises to ensure individuals' specific needs are addressed. ADI members, such as Pakistan (a co-author of this report), are keen and eager to get involved but are at times ignored by humanitarian actors. Many of the solutions exist already and through collaboration we can ensure that no one is left behind in an emergency because of their dementia. We hope the report will shine a spotlight that will mean people living with dementia will never be ignored again.

**Paola Barbarino,**  
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# Contents

Glossary	1
Executive summary	3
<b>Chapter 1: Introduction</b>	<b>6</b>
<b>Chapter 2: Dementia &amp; emergencies – key issues</b>	<b>12</b>
2.1 Left behind	12
2.2 Health and care needs	16
2.3 Food insecurity and malnutrition	23
2.4 Mental health consequences of emergencies and dementia	24
2.5 Social factors	25
<b>Chapter 3: Relevant international standards and frameworks</b>	<b>29</b>
3.1 The Core Humanitarian Standard on Quality and Accountability	29
3.2 The Sendai Framework	29
3.3 Charter on Inclusion of Persons with Disabilities in Humanitarian Action	30
3.4 2030 Agenda for Sustainable Development	31
3.5 Madrid International Plan of Action on Ageing	31
3.6 IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action	32
3.7 IASC 2007 Guidelines on Mental health & Psychological Support in Emergencies Settings	32
3.8 2010 Health Information System on refugees	32
3.9 Integrated Refugee Health Information System	33
3.10 The Sphere Handbook 2018	33
3.11 ADCAP Humanitarian Inclusion Standards for Older People and People with Disabilities	33
<b>Chapter 4: Dementia focused frameworks and tools</b>	<b>35</b>
4.1 Global Action Plan on the Public Health Response to Dementia	35
4.2 WHO Mental Health Gap Action Programme	36
4.3 Global Dementia Observatory	37
4.4 Local dementia-focused tools	37
<b>Chapter 5: Recommendations and areas for action</b>	<b>39</b>
5.1 Recommendations	39
5.2 Areas for action	39
Endnotes	42
<b>Case studies</b>	
Milagros’ story – Puerto Rico in the aftermath of Hurricane Maria	8
Civil society leadership in Pakistan emergency response	14
Begum’s story – Cox’s Bazar, Bangladesh	15
Constantia’s story – Hurricane Irma, Sint Maarten	17
Utilising civil society expertise in Iran	18
Puerto Rico’s older people go without humanitarian assistance	21
Assessing for dementia in humanitarian settings	22
Dementia and Syrian refugees in Jordan	24
Past experiences and person-centred approaches	25
Hurricane Irma – the importance of family support networks	26
Culture, context and mental health of Rohingya refugees in Bangladesh	26
Taking lessons from emergency services	28
Dementia Friendly Initiatives	35
Learning from a crisis – Japan’s preparedness approach	38

# Glossary

**Accessibility:** Accessibility means ensuring that people with disabilities are able to have access to the physical environment around them: to transportation; to information such as reading material; to communication technology; and systems on an equal basis with others. Accessibility requires forward thinking by those responsible for delivery of private and public services to ensure that people with disabilities can access services without barriers.<sup>2</sup>

**Accountability:** In disaster situations there is an increased risk of mismanagement and misappropriation of available funds and resources, which deprives people living in poverty and exclusion of the support they are entitled to. Accountability can be understood as an obligation on the part of decision-makers or those with power to account for the use of their power. Accountability is usually seen as being about compliance and counting: assigning performance indicators and safeguards against corruption and inertia. But accountability is fundamentally about shifting the balance of power. Through raising their voice and exercising their rights, people can demand just and accountable governance.<sup>3</sup>

**Barriers:** Barriers can be defined as factors that prevent a person from having full and equal access and participation in society. These can be physical barriers (such as the presence of stairs and the absence of a ramp or an elevator); social barriers (such as negative attitudes and perceptions of older people or people with disabilities) and institutional barriers (such as policies that can lead to discrimination against certain groups). Some barriers exist prior to the conflict or natural disaster; others may be created by the humanitarian crisis or response. For example, flood water may prevent access to a health centre, or there could be risk of injury entering the conflict zone to access pensions or health services.<sup>4</sup>

**Cognitive disability:** The term cognitive disability refers to a range of disabilities affecting cognitive function, of which can vary in severity. Dementia is a condition causing cognitive disabilities.

**Dementia:** Dementia is an umbrella term for diseases affecting memory, other cognitive abilities and behaviour that interfere significantly with a person's ability to maintain their activities of daily living. Although age is the strongest known non-modifiable risk factor for developing dementia, it is not a normal part of ageing.<sup>5</sup> Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Alzheimer's disease is the most common cause of dementia, but not the only one. The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia.<sup>6</sup> See page 12 for further information on the stages of dementia.

**Humanitarian actors:** Multiple humanitarian actors with different objectives, principles and *modi operandi* intervene in situations of armed conflict and internal violence in order to alleviate the plight of the victims of those situations: governmental and non-governmental organisations, international organisations, national Red Cross and Red Crescent societies, private companies and even the armed forces.<sup>7</sup>

**Humanitarian crisis/emergency/disaster:** A humanitarian crisis, emergency or disaster is defined as a singular event or a series of events that are threatening in terms of health, safety or wellbeing of a community or large group of people, and requires action that is usually urgent and often non-routine.<sup>8</sup> Disasters can be considered large-scale emergencies that result in a serious disruption of the functioning of a community or a society involving widespread human, material, economic or environmental losses and impacts, which exceeds the ability of the affected community or society to cope using its own resources.<sup>9</sup> See information box on page 9.

**Humanitarian response/action:** The collective actions of states and local, national and international humanitarian actors responding to an emergency. Each state has the responsibility first and foremost to take care of the victims of natural disasters and other emergencies occurring on its territory.<sup>10</sup> Humanitarian actors must provide assistance in accordance with the principles of humanity, neutrality and impartiality, established in international law and humanitarian legislative directives adopted by UN inter-governmental bodies.<sup>11</sup> Promoting and ensuring compliance with the principles are essential elements of effective humanitarian coordination.<sup>12</sup>

**Inclusion:** The aim of inclusion in a humanitarian response is to embrace all people irrespective of race, gender, age, disability, ethnicity, religious, medical or other need. An inclusive humanitarian response means a rights-based approach to humanitarian programming, aiming to ensure persons with disabilities have equal access to basic services and a voice in the development and implementation of those services. At the same time it requires dedicated efforts to address and remove physical, social and institutional barriers.<sup>13</sup>

**Mental health and psychosocial support (MHPSS):** Mental Health and psychosocial support is used to describe any type of local or outside support that aims to protect or promote psychosocial well-being or prevent or treat mental disorders. MHPSS responses encompass various levels of support, coordinated through different sectors, in a multi-layered model.<sup>14</sup>

**Non-communicable disease:** Non-communicable diseases (NCDs) also known as chronic diseases, tend to be of long duration and are the result of a combination of genetic, physiological, environmental and behavioural factors. The main types of NCDs are cardiovascular diseases (like heart attacks, high blood pressure and stroke), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma), diabetes, and mental and neurological conditions like dementias.

**Organisations of people with disabilities, or disabled people's organisations (DPOs):** Disabled people's organisations are usually self-organised organisations where the majority of control at board level and at membership level is with people with disabilities. Their role is to provide a voice of their own, on all matters related to the lives of people with disabilities.<sup>15</sup>

**Palliative Care:** Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

**Persons with specific needs:** It is recognised that proactive measures must be taken to actively identify people with specific needs. The United Nations High Commissioner for Refugees (UNHCR) recognises that the following are groups considered to have specific needs: girls and boys at risk, including unaccompanied and separated children; persons with serious health conditions; persons with special legal or physical protection needs; single women; women-headed households; older persons; persons with disabilities; and persons with a diverse sexual orientation or gender identity.<sup>16</sup> People with dementia are clearly persons with specific needs and should therefore be recognised by humanitarian actors.

**Protection:** All activities aimed at obtaining full respect for the rights of the individual in accordance with the letter and the spirit of relevant bodies of law (i.e. International Human Rights Law, International Humanitarian Law and International Refugee Law). Protection is placed at the centre of humanitarian action to ensure people caught up in an emergency are safe from harm, such as violence, abuse and exploitation.<sup>17</sup>

**Psychosocial disability:** An internationally recognised term under the United Nations Convention on the Rights of Persons with Disabilities, used to describe the experience of people with impairments and participation restrictions related to mental health conditions. These impairments can include a loss of ability to function, think clearly, experience full physical health, and manage the social and emotional aspects of their lives.<sup>18</sup> The concept of disability is helpful in raising awareness of people's right to be treated equally and fairly.<sup>19</sup> Within this report we consider the broad term 'psychosocial disability' to include cognitive disabilities such as dementia.

**Resilience:** This refers to the ability of individuals, communities or countries to anticipate, withstand and recover from adversity – be it a natural disaster or crisis. Resilience depends on the diversity of livelihoods, coping mechanisms and life skills such as problem-solving, the ability to seek support, motivation, optimism, faith, perseverance and resourcefulness.<sup>20</sup>

**Vulnerability:** The conditions determined by physical, social, economic and environmental factors or processes which increase the susceptibility of an individual, a community, assets or systems to the impacts of hazards.<sup>21</sup>

## Humanitarian emergencies

A humanitarian emergency can strike without warning or can be slow-onset, emerging gradually over time, often based on a confluence of different events.<sup>22</sup>

According to the United Nations International Strategy for Disaster Reduction, emergencies are caused by natural hazards (such as earthquakes, cyclones, forest fires, floods, heatwaves and droughts), epidemic and pandemic diseases, transport crashes, building fires, chemical, radiological and other technological hazards, food insecurity, conflicts, and situations such as mass gathering events.<sup>23</sup>

The Sendai Framework recognises that disaster risk reduction can include natural and man-made hazards and related environmental, technological and biological hazards and risks.<sup>24</sup>

The ongoing protracted nature of the world's conflicts remains the main driver of humanitarian needs, while natural disasters continue to cause many people to need emergency aid.<sup>25</sup> Recovery for populations affected can take months and years. Increasingly, humanitarian actors are responding to long-term protracted crises. In 2018, approximately 86 per cent of funding received was for responses to protracted crises lasting longer than five years.<sup>26</sup>

# Executive summary

Worldwide, around 50 million people have dementia, with nearly 60 per cent living in low- and middle-income countries. Every year, there are nearly 10 million new cases – that’s one every three seconds. The total number of people with dementia is projected to reach 82 million in 2030 and 152 million in 2050. Much of this increase is attributable to the rising numbers of people with dementia living in low- and middle-income countries, many of which are experiencing rapid population ageing.<sup>27</sup>

One in every 70 people around the world is impacted by crisis and urgently needs humanitarian assistance and protection.<sup>28</sup> People living with dementia are largely overlooked in humanitarian response. Those with a so-called ‘hidden’ disability like dementia can be left behind in receiving humanitarian assistance if those responding do not ‘see’ their condition.

The United Nations High Commissioner for Refugees (UNHCR) recognises that persons with serious health conditions, persons with special legal or physical protection needs, older persons and persons with disabilities are groups considered to have specific needs.<sup>29</sup> Under this UNHCR criteria people with dementia are clearly persons with specific needs and should therefore be recognised by humanitarian actors.

Humanitarian actors must provide assistance in accordance with the principles of humanity, neutrality and impartiality. Despite these principles established in international law and humanitarian legislative directives adopted by UN inter-governmental bodies, people living with dementia are routinely excluded from humanitarian assistance.

We have a collective responsibility to ensure no person with dementia is left behind because of their health condition. Greater sensitisation and collaboration is urgently needed between humanitarian agencies, governments, inter-governmental organisations, non-governmental organisations (NGOs), disabled people’s organisations (DPOs) and donors.

## Frameworks, standards, tools

Existing humanitarian frameworks go some way to protecting people most at risk during a humanitarian crisis, but do not yet meet the specific needs of people affected by dementia. Support to remove physical barriers to leaving an emergency situation is advocated in many of the frameworks, however there is a lack of understanding of the physical barriers affecting people with dementia. There is also a lack of guidance on removing social barriers, including stigma and negative attitudes older persons and persons with disabilities.

States and non-state humanitarian actors are clearly mandated by existing frameworks to provide adequate accessible and continuous care for those living with chronic conditions, yet inadequate attention is paid to dementia.

The number of different frameworks, approaches and lack of standardisation can be a barrier to ensuring the needs of people living with dementia are met in humanitarian response. Due to the breadth of existing guidelines and organisational protocols already in existence, it is clear that the development of specific guidelines on dementia in humanitarian settings would be too specific for realistic uptake.

The Humanitarian Inclusion Standards for Older People and People with Disabilities developed by the Age and Disability Capacity Programme (ADCAP), offer important guidance which if well implemented should improve the support of people affected by dementia.<sup>30</sup>

The upcoming Inter-Agency Standing Committee (IASC) Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action provide an opportunity to adequately address all disabilities. Tools such as the World Health Organization (WHO)’s mhGAP Intervention Guide (mhGAP-IG) and Training Manual and the Washington Group Extended Set of Questions are currently underused, yet they are invaluable tools in supporting the needs of people living with dementia in humanitarian settings and should be utilised uniformly in all humanitarian settings.<sup>31</sup>

The WHO Global Action Plan on the Public Health Response to Dementia 2017-2025, unanimously adopted by WHO Member States in May 2017, outlines that ‘planning responses to and recovery from humanitarian emergencies must ensure that individual support for people with dementia and community psychosocial support are widely available.’<sup>32</sup> The wider targets and recommended activity within the Global Plan provide crucial guidance for governments and local, national and international partners to advance health and care system strengthening to meet the needs of people affected by dementia. This in turn will help to improve the resilience and preparedness of countries to support those living with dementia when humanitarian emergencies do occur.

## Dementia awareness

Globally there has been a persistent lack of understanding that dementia is a medical condition rather than a normal part of ageing, and broader stigma is still widely associated. Misconceptions of dementia can fuel assumptions, negative attitudes, discrimination and even harm from violence.

Frequently those living with dementia and other cognitive disabilities do not present themselves in humanitarian settings, meaning humanitarian actors are unaware of, and not looking for, this at-risk population and therefore not addressing the scale of the issue. More can be done to create dementia awareness for those involved in strategic planning for humanitarian emergencies, as well as wider staff through training and dissemination of information.

Dementia awareness should be included in preparedness programmes for disaster prone or unstable communities, as demonstrated in Japan. These actions will help to ensure humanitarian actors understand the need to screen for and manage dementia and communities are sensitised to respond. Preparedness can also help to ensure community members are able to recognise the symptoms of people living with dementia, reducing reliance on rescue workers.

Humanitarian actors need to work with specialist organisations, for instance dementia-specific organisations, to fill gaps in health and social care expertise. Planning and delivering preparedness activities should be done in consultation and collaboration with people living with dementia, to ensure their specific needs and rights are addressed.

### Data collection and research

The lack of awareness of dementia means this at-risk population is often hidden and therefore the scale of the impact is not apparent. This leads to a lack of assistance.

Donors should add funding stipulations for inclusive and robust data collection to ensure people with cognitive disabilities like dementia, and wider psychosocial disabilities, are included in humanitarian response. More accurate and comprehensive data must be routinely collected as part of disaster preparedness and during the rapid needs assessment stage. It is equally important to analyse, report and utilise the data that is collected. Working with partner DPOs (including those representing people with dementia) will improve data collection processes, as will the use of the Washington Group Extended Set of Questions, the integrated Refugee Health Information System (iRHIS), and WHO's mhGAP tools. However, support to people affected by dementia during humanitarian response should not wait for improved data collection. The urgent need is now. As the seventh leading cause of death worldwide, and a major cause of disability and dependence among older adults, in any given emergency, the burden of proof should not be about identifying cases of dementia to demonstrate a need for action, but to make the assumption that this population exists.

There is a distinct lack of data and research on the scale of dementia and humanitarian emergencies and the issues surrounding it. The sector would benefit from widening the evidence base to explore the experience and protection needs of people affected by dementia in emergencies, and best practice in the form of well evaluated pilot studies to demonstrate the benefits of inclusive health interventions in humanitarian settings.

### Collaboration between humanitarian agencies and dementia specialists

Those involved in humanitarian response cannot be expected to be experts in all conditions, therefore collaboration between humanitarian agencies, dementia specialists and people living with dementia must be encouraged via local, national and global DPOs. Disability expertise exists in almost every situation where humanitarian actors respond. To focus on promoting the full rights and dignity of all people with disabilities, humanitarian actors need to ensure that people with disabilities are fully engaged as active agents of change and rights holders in line with the Convention on the Rights of Persons with Disabilities (CRPD). They need to take into account that not all people living with dementia identify as having a disability and therefore might not be represented by local DPOs. Care must be made to ensure people with younger-onset dementia are not overlooked as they may not fit within with bandings often associated with dementia such as age. Equally, older people living with dementia should not be assumed to have diminished capacity to contribute (with or without support) in decision-making that affects their lives. Dementia affects every person differently.

Dementia and older people's NGOs, most obviously the national Alzheimer association in an affected country, can help to fill gaps in health and social care expertise. Dementia-focused organisations can provide specialist input on programme design and during emergency response (for example within coordination committees, as workers or volunteers on the ground, or in an advisory capacity). Wider organisations addressing specific needs of people living with dementia, such as palliative care, can also provide expertise and experience in humanitarian settings.

### Holding humanitarian actors to account for implementing best practice

The stronger and most relevant protections for people living with dementia are found in the frameworks of non-binding standards and guidelines, meaning they are voluntary with no discernible consequences if not met. This leads to the issue of ownership - who is responsible for enacting guidance in the absence of compliance mechanism? As with all frameworks that aim to improve practice, issues of translating good intentions into successful implementation remain. The leadership of humanitarian agencies and organisations already have competing demands for resource allocation and so unmonitored targets may be deprioritised. Guidance on making humanitarian action more inclusive should be evidence-based, co-ordinated, accessible and practical. This is to ensure uptake by those in the field, and ultimately to translate into improving the lives of those with dementia in humanitarian emergencies.

Ultimately, every time a person is denied assistance or protection during an emergency response because of their dementia status, humanitarian organisations are ignoring their obligation to operate without prejudice. The exclusion of people affected by dementia from humanitarian efforts cannot continue, and humanitarian actors must recognise some of the most hidden among those they support.

## Recommendations

- 1 Ensure accessibility** by eliminating the physical, communication, social/attitudinal and institutional barriers to the inclusion of those with dementia in humanitarian action.
- 2 Develop and universally use fully inclusive frameworks, standards and tools** to ensure support for people with dementia in humanitarian emergency response.
- 3 Create dementia awareness** initiatives to aid disaster preparedness, humanitarian workforce understanding and community resilience in humanitarian emergencies.
- 4 Collect, analyse, report and utilise disability disaggregated data** which includes cognitive disability, and ensure the data is accessible to all humanitarian actors.
- 5 Widen the evidence base** on the impact of dementia in humanitarian settings and solutions to support people living with the condition.
- 6 Foster collaboration between humanitarian agencies and dementia specialists** via local, national and global NGOs/DPOs and people living with dementia, to provide specialist input across the humanitarian programme cycle, from preparedness plans to evaluation.
- 7 Monitor inclusion of people living with dementia** as part of improved inclusive action for those with cognitive and psychosocial disabilities in humanitarian programming.
- 8 Invest in inclusive humanitarian action** ensuring data collection and monitoring for cognitive and psychosocial disabilities is included within funding requirements to ensure those living with dementia are not left behind.
- 9 Dementia-focused NGOs** and disabled peoples organisations develop processes for emergency preparedness and response and advise humanitarian actors on dementia-specific needs and best practice.

# Introduction

## **Dementia – leave no one behind**

One in every 70 people around the world is impacted by crisis and urgently needs humanitarian assistance and protection.<sup>33</sup> More people are being displaced by conflict, food insecurity is rising and due to climate change, natural disasters are becoming more frequent. Globally, 131.7 million people will need humanitarian assistance and protection in 2019.<sup>34</sup>

To date, dementia in humanitarian crises has been unrecognised and inadequately addressed. So why should we address the impact of dementia in humanitarian response?

The United Nations (UN) High Commissioner for Refugees recognises that persons with serious health conditions, persons with special legal or physical protection needs, older persons and persons with disabilities are groups considered to have specific needs. People with dementia are clearly persons with specific needs and should therefore be recognised by humanitarian actors.

All involved in humanitarian action (including states, local, national and international non-governmental organisations, international organisations and private organisations) must provide assistance in accordance with the principles of humanity, neutrality and impartiality.<sup>35</sup> These principles are established in international law and humanitarian legislative directives adopted by UN intergovernmental bodies.<sup>36</sup> Yet people living with dementia, alongside millions of older people, people with cognitive, psychosocial and other disabilities, are too often excluded from humanitarian assistance. They are largely overlooked by humanitarian actors as they can be the hardest to reach.<sup>37</sup>

The critical need to ensure people living with dementia are able to exercise their right to humanitarian assistance is particularly acute in low- and middle-income countries, where diagnosis is low<sup>38</sup> and humanitarian emergencies are more widespread. Programme design and delivery (including needs assessment, recovery, assistance and monitoring) must be developed with the involvement of relevant disabled persons' organisations (DPOs) and the involvement of people affected by dementia.

The inclusion of 'people affected by dementia' not only refers to the person living with the condition but also their families and those who provide informal care support. Persons providing care support can also be disproportionately affected during a humanitarian emergency. They may be responsible for supporting with decisions on when and how to escape from the situation. They can also play a crucial role in supporting access to humanitarian assistance, yet too often find themselves providing continuous health and care support to loved ones, without the specialist support from humanitarian actors or emergency services.

People living with dementia are typically not explicitly included in the publically available safeguarding and protection policies of major humanitarian agencies. Initial exploration of humanitarian agencies' safeguarding policies and resources demonstrates not only a lack of reference to dementia, but also few with adequate reference to terms such as mental health and psychosocial support (MHPSS), cognitive disability, psychosocial disability, cognitive and neurological conditions – all umbrella terms that should ensure people living with and affected by dementia are supported. Few also refer specifically to older persons, suggesting a lack of focus on the population group most likely to experience dementia. Consultation with humanitarian actors during research for this report, demonstrated a lack of sector awareness of dementia, and a lack of prioritisation compared to other conditions.

There is growing recognition that a one-size-fits-all humanitarian response fails to identify and address persons with specific needs or marginalised groups. Where systems are adapted, priority groups are usually those injured as a result of the emergency or young children and their mothers.<sup>39</sup> It is time that people with disabilities, including those with acquired disabilities like dementia, are widely recognised as a priority group with multiple identities.

In a humanitarian emergency, experiences of those living with dementia will vary from person to person. Variables could include the nature of the emergency, the extent of existing health and social care infrastructure, inclusivity of assistance provided, and how well people living with dementia or with similar cognitive disabilities are included in the planning, coordination, delivery and monitoring of the response. Ultimately, ensuring the inclusion of people living with and affected by dementia in humanitarian response is a collective responsibility, involving humanitarian agencies, governments, inter-governmental organisations, local partners, DPOs, donors, and crucially, consultation with affected populations themselves. It requires collaboration, leadership, funding, resources and accountability.

The purpose of this research report is to raise the profile of those living with dementia as an under-recognised and under-served group at risk of not receiving assistance in humanitarian response, and to recommend improvements in policy and practice. The report explores the barriers (social exclusion, stigma and discrimination and lack of awareness) and proposed solutions, so that no-one is left behind in the humanitarian response simply because of their medical condition or their disability.

*“Addressing needs of people living with dementia during emergencies is a humanitarian and public health blind spot. We rarely see the needs of this population group reflected in assessments or programmes in humanitarian responses. Time is now for advocacy among decision makers, capacity building of humanitarian responders, engagement of communities including older adults and their care givers and resource allocation. Time is now to do more and do better for people living with dementia and older adults during and after emergencies.”*

**Fahmy Hanna – WHO Geneva, Co-Chair of IASC Reference Group on Mental Health and Psychosocial Support in Emergencies**

### **Dementia – a global health priority**

Dementia is recognised as a public health priority by the World Health Organization (WHO). Every three seconds someone in the world develops the condition. At least 50 million people live with dementia worldwide and this number is growing by 10 million each year.<sup>40</sup> More than half of people living with dementia worldwide (60 per cent) live in low- and middle-income countries.<sup>41</sup> It is listed by WHO as the world’s seventh leading cause of death and is recognised as a major cause of disability and dependence among older adults.<sup>42</sup>

Dementia as a condition is variously classed as a psychosocial disability, a cognitive disability or impairment, a neurological condition, a mental health condition, a medical condition and a non-communicable disease. Throughout this report we refer to dementia using a number of these terms, depending on the context however we mainly use the term ‘cognitive disability’ which is the term preferred by Dementia Alliance International. See page 12 for more information on the stages and symptoms of the condition.

### **Recognising the capacity of people with dementia and local organisations**

Involving a wide range of people living with dementia is paramount during the planning and design of emergency response plans, to ensure the specific needs of people living with dementia are addressed. Many persons with dementia are very capable of representing themselves, or speaking up for those who are no longer able to do so. This is one of the key messages from Dementia Alliance International, an organisation globally representing persons with dementia.<sup>44</sup>

*“Our work on claiming the human rights for all people with dementia means we are legally entitled to be included, and not just consulted, or represented by others.”*

**Dementia Alliance International**

Due to its cognitive nature, dementia can be “invisible” and in a humanitarian crisis its symptoms can also be misinterpreted as a psychological response to a crisis, rather than an underlying medical condition. Misconceptions of dementia can fuel assumptions, negative attitudes and discrimination leading to a lack of prioritisation for help. In addition, people living with dementia may be leading unnecessarily restricted lives and kept at home for their safety or because of associated stigma.<sup>43</sup> While everyone experiences dementia differently, for many the condition causes increasingly severe acquired and progressive cognitive and physical disabilities that can result in the loss of ability to carry out every day activities. As a progressive condition, the symptoms change and can become more acute over time, leading to disability in older people. Thus the ability to cope with the impact of a humanitarian emergency can vary considerably for those living with dementia. It is also important to note that people living with dementia do not constitute as one unified group, not all will experience the condition or disability in the same way.

Globally, there has been a persistent lack of understanding that dementia is a medical condition rather than a normal part of ageing, and broader stigma is still widely associated. Dementia policy and programming may be included under various health sub-sectors such as ageing, mental health, disability/inclusion and non-communicable diseases. In recent years huge strides have been made in regards to the recognition of dementia as a global health crisis, and in the development of policy and practice to support people living with the condition. However, in some cultures there is no word for dementia, and in others the term is deeply stigmatised. People living with the condition in many parts of the world desperately need access to diagnosis, health and social care.

Donors must recognise the importance of local and national partners working for and alongside people with dementia. Increased funding to these organisations will be vital in ensuring they have the capacity to respond, outside of their regular activity. The Grand Bargain – a key outcome of the 2016 World Humanitarian Summit is an agreement between more than 30 of the biggest donors and aid providers and commits to providing 25 per cent of global humanitarian funding to local and national responders by 2020.<sup>45</sup> This commitment, as well as ensuring increased multiyear funding, could in principle provide local and national DPOs and dementia specialist organisations with greater predictability and continuity, in the delivery of support for people with dementia and other cognitive or psychosocial disabilities in humanitarian emergencies.

WHO has set a global target for 75 per cent of countries to have developed or updated national policies, strategies, plans or frameworks for dementia (either stand-alone or integrated into other policies/plans) by 2025.<sup>46</sup> Yet at the start of 2019, just 32 member states and territories have adopted plans, and 31 are in development.<sup>47</sup> With few countries addressing this target there continues to be a monumental reliance on familial and

social networks for the care of people living with dementia, and a lack of official data management to acknowledge the scale of dementia in many countries. These difficulties further compound the crisis faced by people living with dementia in humanitarian emergencies, when the existing health systems or social networks relied upon breakdown.

Case study:

### **Milagros' story – Puerto Rico in the aftermath of Hurricane Maria**

Milagros Negrón lost her husband, Othni Rodríguez, to Alzheimer's Disease because of the lack of health services in her community after Hurricane Maria devastated Puerto Rico in September 2017.

*"It was a very difficult time. Puerto Rico was not prepared to deal with this hurricane neither the general public nor the government. We went through hardships. Among these hardships, a lot of victims lost their lives. Among these victims was my husband who died as a consequence.*

*The impact on people living with dementia was severe. They seemed more disorientated than usual. Caregivers were also struggling, many of them without water or power. The situation was very, very difficult on all of them.*

*I had to think for him [my husband] and for myself – I was his primary caregiver. It affected me and my family because I had a lot of weight on my shoulders. It was very difficult, both emotionally and economically.*

*There was no type of assistance for Alzheimer patients, there was no aid for them, none at all. There were patients that struggled a lot. There's no registry in Puerto Rico for these patients. Aid workers, such as the Civil Defence were not seen. They were unprepared to deal with Alzheimer's patients. There was so much need, that many had to be transferred to the United States, because there wasn't enough help."*

*"The amount of assistance and care needed throughout the emergency to aid patients with dementia was far too much - it was scarce. In fact, I had to go around my community offering aid to those in need, among them people with dementia. The government was not providing aid, so the caregivers would go out to the streets looking for help."*

Milagros says there are ways support could have been improved.

*"If the government was better prepared; if people working in Civil Defence were present providing aid and better prepared.*

*When I was in need of help, because my husband's health deteriorated during the hurricane. I dialled*



Milagros Negrón © Cromance Foto

*911 approximately twenty-two times. The calls were answered but no one arrived at my home.*

*Too many people died in their homes, whether it was a nursing home or their own, which is how my husband lost his life.*

*You can find aid for cancer and Parkinson's [for example], but you'll find that Alzheimer's is like an afterthought, even though we have a very large population with Alzheimer's. If our government had more awareness about this disease there would actually be more resources for these patients."*

Milagros believes future emergency response can be improved through dementia awareness.

*"Our people are not well educated about this disease; neither the people nor the government. We need to educate the masses. Educated people could be of big help for Alzheimer's patients, starting with the government, schools and the different departments, including health.*

*My life after the crisis has been very difficult. Losing my husband under those circumstances, though it was known he had Alzheimer's disease, and I knew that at some point he would die, I never imagined it would happen like this."*

Milagros continues to offer her support to people living with dementia in Puerto Rico as a Board Member of Asociación Alzheimer Y Desórdenes Relacionados de Puerto Rico.

### Older persons with disabilities in emergencies

Older people are among those at highest risk in humanitarian crises.<sup>48</sup> An estimated 26 million older people are affected by natural disasters annually.<sup>49</sup> As dementia prevalence increases significantly with age, leading to disability in older people, those with the condition are at significant risk of exclusion from humanitarian assistance. Older persons with disabilities face specific barriers and risks during a humanitarian response. Many older people have one or more chronic non-communicable diseases (co-morbidities). Alongside dementia, cardiovascular disease, stroke, diabetes and dementia are common.<sup>50</sup> Inability to access support for their specific needs can become a serious challenge to survival and wellbeing.<sup>51</sup>

In some countries older people are more likely to live in rural or coastal areas with fewer services.<sup>52</sup> These environments can face higher risk of natural disasters and may be far away from the infrastructure required for humanitarian responses.<sup>53</sup> When an earthquake and tsunami struck Japan in 2011, 56 per cent of those who died were aged 65 and over, although only 23 per cent of the population is in this age group. In the Philippines, 38 per cent of the fatalities in Typhoon Haiyan in 2013 were aged over 60 years, although older people constitute just 7 per cent of the population. In Nepal, 29 per cent of those who died in the earthquake in 2015 were aged over 60, yet older people are only 8.1 per cent of the population. In 2005, 71 per cent of those who died in Hurricane Katrina in the United States (US) were 60 years or older.<sup>54</sup>

Whilst dementia is most common in older people, assumptions and stereotypes must not be made on what people living with dementia look like. Dementia can be developed from a young age, though this is rarer and can vary in severity.

### A growing yet unquantified challenge

Whilst dementia is not a normal part of ageing, age is the largest known non-modifiable risk factor for developing the condition.<sup>55</sup> As the leading organisations involved in the Age and Disability Capacity Programme (ADCAP) recognise, older people and people with disabilities are routinely excluded from humanitarian responses.<sup>56</sup> The global population of persons aged 60 and over is rising dramatically – especially in regions that have the greatest risks of natural or conflict-related

disasters.<sup>57</sup> Both the absolute numbers and proportion of older people globally are rapidly growing.

The number of people over 60 is projected to increase to 1.4 billion in 2030, and to 2.1 billion by 2050.<sup>58</sup> Growth will continue to be greatest in developing regions, which will have an estimated 1.7 billion people aged 60 years or older in 2050.<sup>59</sup> Global demographic change has implications for the response to humanitarian crises.<sup>60</sup> Rapid population ageing places a huge strain on existing health and social care systems even before a disaster strikes, which governments are currently ill-equipped to address. Understanding the numbers and needs of different groups within an affected population also requires knowledge of contextual factors.<sup>61</sup>

The number of people living with dementia affected by humanitarian emergencies is unknown, mainly due to a lack of existing national data and a lack of systematic data collection during emergency response. Humanity and Inclusion, a leading INGO working in disaster and conflict settings, state more broadly that humanitarian actors do not know how many persons with disabilities are affected in a given crisis.<sup>62</sup> Studies and data on the impact of disasters on people with disabilities, including dementia, are scarce. Some studies show that disasters disproportionately place people with disabilities and their families in more at-risk situations.<sup>63</sup> Without knowing the number of persons with disabilities, humanitarian actors are ill-equipped to identify and address the needs of persons with dementia and other cognitive disabilities, in order to design and implement inclusive projects.

This is reflected in the lack of specific programme funding for people with disabilities. Humanity and Inclusion and HelpAge International analysed over 6,000 UN projects between 2010 and 2011 and found only one per cent of humanitarian funded projects were for older people or people with disabilities.<sup>64</sup> Robust data and information management systems must be developed to promote inclusion of persons with dementia in humanitarian response, helping to identify their specific needs and ensure inclusive programme delivery. Disability data needs to be routinely collected as part of disaster preparedness, and within the assessment and subsequent stages of humanitarian



### Missing Millions

*Missing Millions* is a comprehensive 2018 study by HelpAge International and the London School of Hygiene & Tropical Medicine.<sup>65</sup> The report focuses on the millions of older people with disabilities at risk of being excluded from humanitarian assistance. The study drew upon a comprehensive literature review, data analysis, and interviews with older people with disabilities affected by crises in Tanzania and Ukraine. Data analysis revealed that between 7.8 and 13.7 million older people with disabilities are currently affected by humanitarian crises.<sup>66</sup> However, the study found that there is insufficient attention to older people with disabilities and their needs are not well met by humanitarian actors. Older people who were interviewed reported physical and institutional barriers accessing assistance. They also reported attitudinal barriers and at times were made to feel humiliated trying to access their rights.

response, using tools such as the Washington Group Extended Set of Questions.<sup>67</sup> Standardisation of data collection methods should be considered alongside the potential for a 'disability marker' following the lead of the 'Gender with Age Marker' introduced to assess how gender is incorporated in humanitarian projects.

*“Humanitarian responses do not always provide for the distinctive needs of older people and people living with disability including dementia. As a result they too often struggle to have their voices heard and their needs met. There is a pressing need both to increase the awareness and understanding among humanitarian agencies and staff of the specific challenges likely to be faced in such crises by both older people and people living with dementia and to provide tools and strategies to offer more appropriate and effective help.”*

**Chris Roles – Director, Age International**

### Dementia as a disability

Too often dementia is misunderstood as a normal part of ageing, rather than the progressive and terminal medical condition that it is, and a leading cause of disability in older people. Dementia will impact people in different ways depending on the type of the condition and other factors. Dementia causes increasingly severe cognitive and physical disabilities that can result in the loss of ability to carry out every day activities. This is compounded by physical and societal barriers which can be further disabling. The level of disability associated with the condition will vary from person to person and may change over time. Disability means different things to different people. Not everyone with dementia will want to identify as having a disability, however there are arguments for the benefits of recognising dementia as an acquired disability. For example, people living with dementia may find it helpful and empowering to identify or be identified as a person with disability and it can help them to access support. It can also be helpful, for those who want to, to group together to campaign collectively for rights and to raise awareness about disability.

A person with dementia, however, should not have to accept the label of either disease or disability in order to have their human rights upheld.<sup>68</sup> Both dementia and disability are frequently associated with stigma. Accepting or being labelled as having a disability may have an emotional and psychological impact. This may lead to people feeling devalued and fearing discrimination, even in the absence of any negative reaction from other people. People in humanitarian emergencies can feel particularly at risk in this regard. It is also important to note that people living with dementia do not constitute one unified group, not all will experience the condition or disability in the same way.

In this report we recognise dementia as an acquired disability and therefore covered under the UN's Convention on the Rights of Persons with Disabilities. For further analysis see the publication *Access to CRPD and SDGs by Person's With Dementia* by Alzheimer's Disease International and Dementia Alliance International.<sup>69</sup>

### The right to humanitarian assistance

Humanitarian disasters can take many forms – earthquakes, floods, tsunamis or conflicts – and often strike without warning. For people affected, it can be a traumatic ordeal. Worldwide, it is estimated over one billion people experience some form of disability.<sup>70</sup> During a disaster, evidence shows the fatality rate is likely to be two to four times higher for persons with disabilities.<sup>71</sup> The months following an emergency are often as dangerous as the disaster itself. Injured and disabled people face a long, hard fight to return to life as normal.<sup>72</sup>

In the 2016 Report of the United Nations Secretary-General for the World Humanitarian Summit, the UN Secretary-General stated that *“Persons with disabilities and older people, often suffering from physical, mental and mobility limitations, social stigmatization and exclusion, are among the most marginalized. Without targeted national and international efforts, they will continue to face barriers to education, health programmes and livelihoods and be at great risk of abuse, injury and death during conflicts and disasters”*.<sup>73</sup>

The United Nation's Convention on the Rights of Persons with Disabilities (CRPD) requires states to ensure that persons with disabilities are protected in situations of risk or humanitarian emergency (Article 11). It also requires that international cooperation be accessible to, and inclusive of, persons with disabilities (Article 32).<sup>74</sup> This means that states are obliged to promote, protect and ensure the rights of all persons with disabilities within their territory, including those who have been displaced across a border.<sup>75</sup> However, despite persons with disabilities having a right to humanitarian assistance, they are frequently subject to multiple violations of their human rights during humanitarian response, including the right to live with dignity and autonomy. All persons with disabilities face stigma, discrimination and inequalities (for example through acts of violence, abuse, isolation, lack of access to services or adequate support), therefore denying them their right to assistance and protection.<sup>76</sup>

Underlining all humanitarian action are the principles of humanity, impartiality, neutrality and independence.<sup>77</sup> The Humanitarian Principles require humanitarian assistance and protection to be provided on the basis of need, without discrimination.<sup>78</sup> These principles, derived from international humanitarian law, have been adopted by the United Nations in General Assembly Resolutions 46/182 and 58/114. Their global recognition and relevance is furthermore underscored by the Code of Conduct for the International Red Cross and Red Crescent Movement and Non-Governmental Organisations in Disaster Relief, and the Core Humanitarian Standard on Quality and Accountability.<sup>79</sup>

The Humanitarian Principles and CRPD therefore underscore that humanitarian actors must consider the rights and needs of those living with dementia as they design and deliver humanitarian assistance programmes. Thus, in theory, someone affected by a dementia and other cognitive disabilities in a humanitarian response, should be protected, assisted with

dignity and be able to access their full rights. However, research by Humanity and Inclusion found that 75 per cent of persons with disabilities, participating in an online survey, reported not having adequate access to basic humanitarian assistance.<sup>80</sup> 92 per cent of humanitarian actors responding to the survey estimated that persons with disabilities were not properly taken into account in humanitarian response.<sup>81</sup> The research found that persons with disabilities have less access to information about evacuation centres, prevention and preparedness measures, and humanitarian interventions than the general population.<sup>82</sup>

When tailoring humanitarian assistance, it is important to understand that persons with disabilities are a very diverse group of individuals. Humanitarian actors need to look beyond a person's 'disability' and understand the person's multiple and intersecting identities (such as gender, age, race, ethnicity, social hierarchies within a community, socio-economic background etc.) when planning, coordinating and monitoring assistance delivery.<sup>83</sup>

Dementia inclusion is part of a wider disability inclusion movement for inclusive humanitarian aid. The movement, led by people with all types of disabilities, strives for the active participation and representation of all people regardless of age, gender, disability, ethnicity, race, class, religion, sexuality or any other characteristic. Disability-inclusive development is part of this social justice movement that challenges unjust systems and exclusive policies, relations and practice.<sup>84</sup>

Global humanitarian frameworks and tools on inclusion and disability do exist, with progress seen via the Humanitarian Inclusion Standards, an outcome of the Age and Disability Capacity Programme (ADCAP), and the Inter-Agency Standing Committee (IASC) for example. A collective effort and ownership is needed by humanitarian actors, governments, civil society organisations, national and international organisations and donors to implement, fund and monitor progress. Otherwise the needs of people living with dementia and other disabilities will continue to be ignored and side-lined during a humanitarian response.

*"No one should be left behind through the full implementation of the Convention on the Rights of Persons with Disabilities, including people with dementia. Yet most people, even in civil society do not yet see this condition as one that brings with it acquired cognitive disabilities. People with dementia are systematically excluded from rights-based and equitable inclusion; the barriers are far more than dementia. The real barriers are due to stigma, discrimination and misperceptions about the capacity of people with dementia, and many breaches of our most basic of human rights."*

**Kate Swaffer – Chair, CEO & Co founder of Dementia Alliance International**

# Dementia & emergencies – key issues

People living with and affected by dementia face uniquely serious and specific challenges when confronted with the chaos and destruction of a natural disaster, conflict, population displacement or impact of climate change. In the urgency of an emergency, people with less obvious needs can not only be physically left behind, but also find their specific needs unmet.

In 2015, Humanity and Inclusion carried out a consultation of persons with disabilities, disabled people's organisations and humanitarian actors. Three quarters of respondents reported that they did not have adequate access to basic assistance such as water, shelter, food or health. In addition, the specific services that persons with disabilities may need (such as rehabilitation, assistive devices, or access to social workers or interpreters) were not available for half of respondents with disabilities, further impeding their access to mainstream assistance.<sup>85</sup>

The immediate stage of a humanitarian response is geared towards dealing with urgent signs of distress, which can lead to neglect of equally acute, but often less visible, chronic conditions and cognitive or psychosocial disabilities. The main assistance prioritised is food, shelter, water and medicine to save lives. This section explores the impact dementia presents during a humanitarian emergency and at different stages of the condition.

## Stages of dementia: Signs and symptoms

Dementia affects each person in a different way, depending upon various factors including the type of dementia and the stage of the condition. The speed at which dementia progresses varies widely.

Common signs of dementia include: decline of, or problems with, memory (severe forgetfulness) and orientation (awareness of time, place, and person); changes in behaviour such as apathy (appearing uninterested) or irritability; loss of emotional control (easily upset, irritable, or tearful); and difficulties in carrying out usual domestic or social activities.<sup>86</sup> See page 37 for WHO's Dementia Assessment pathway which shows ways to assess cognitive decline by testing memory and/or orientation, for signs of dementia.

Changes in the brain, a person's physical and mental health, their environment and medications can cause changed behaviour. Dementia affects people in different ways and changes in the behaviour or emotional state of a person with dementia are common. Dementia may also cause sensory changes, such as difficulty with spatial awareness, hypersensitivity to noise and certain tones, and a decreased sense of taste which could affect the person's appetite. Changes in the senses may make it difficult for the person to interact with their environment, which could also result in changes in behaviour. However in most cases, behavioural and psychological symptoms of dementia are an

expression of some unmet need (such as thirst) or sensation that the person with dementia is experiencing (for example, frustration, pain, boredom, loneliness, confusion) that they are not able to communicate verbally.<sup>87</sup>

There are over 200 sub-types of dementia, signs and symptoms will vary. However, generally the condition can be understood in three stages.<sup>88</sup>

**Early stage:** The early stage of dementia is often overlooked, because the onset is gradual. Common symptoms include: forgetfulness, losing track of the time, and becoming lost in familiar places.

**Middle stage:** As dementia progresses to the middle stage, the signs and symptoms become clearer and more restricting. These include: memory loss of recent events and people's names; becoming lost at home, having increasing difficulty with communication; needing help with personal care; and experiencing changes in behaviour or emotional state.

**Late stage:** The late stage of dementia is one of near total dependence and inactivity. Memory disturbances are serious and the physical signs and symptoms become more obvious. Symptoms include: becoming unaware of the time and place; having difficulty recognising relatives and friends; having an increasing need for assisted self-care; and having difficulty walking. Difficulty communicating and expressing unmet needs may lead to changes in behaviour.

## 2.1 Left behind

Brutal changes to home, community structure and environment occur during a humanitarian emergency which can place all persons with disabilities at risk,<sup>89</sup> especially those with dementia and with other cognitive disabilities. First and foremost, people living with dementia may not be prepared, willing or able to deal with a humanitarian emergency in the same way as others. This section explores how reduced mobility, reduced capacity and family circumstances can be impacted at different stages of the progressive condition, resulting in people living with dementia facing various unmet needs.

Recovery cannot start without humanitarian actors finding and identifying people with acute needs, including those living with dementia. This is hampered in communities in which dementia is severely stigmatised. People living with dementia are often invisible to humanitarian actors; isolated, or hidden, because of stigma or the possibility of negative reactions from neighbours and relatives to behavioural and psychological symptoms.<sup>90</sup>

A 2012 report from Alzheimer's Disease International highlighted that nearly one in four people living with dementia (24 per cent) hide or conceal their diagnosis, citing stigma as the main reason. Stigma prevents people from acknowledging their symptoms and obtaining the help they need to live well with dementia.<sup>91</sup>

This stigma may cause people living with dementia or their families to be reluctant in presenting themselves to humanitarian staff, emergency registration desk or camp management. In addition, it is common for some people living with dementia to spend long periods of time walking around in their home or trying to leave their home to walk outside – this can lead to over-protective behaviour of those supporting them. During the immediate aftermath of the disaster, people living with dementia may therefore remain behind locked doors, hidden inside homes or institutions, and not presenting themselves to humanitarian actors, due to stigma and social-cultural discrimination.

Consideration of practical approaches should be made to identify persons locked in homes or hidden away and not presenting themselves to humanitarian actors, due to stigma and social-cultural discrimination. Initiatives should include training community outreach volunteers and staff to identify and support people with dementia. Lessons could be learned from initiatives to address other stigmas or to support hard to reach groups.

### **Challenges identifying people living with dementia**

The identification of people living with dementia may be hampered if care supporters are casualties of a disaster, and these problems can be exacerbated by loss of community support structures. Health Information Systems, where they exist, may contain data related to disabilities although rarely, at present, to the level of detail to include dementia. More commonly reliance is on local community knowledge and this must change. Identification is further complicated by a lack of dementia awareness in the general population in many communities, meaning symptoms have remained undiagnosed and needs unmet for prolonged periods even before a humanitarian crisis.

In the absence of access to local data, proactive effort may be needed in the recovery stage. Older persons may not receive a diagnosis of dementia as it is commonly misunderstood as a normal part of ageing. Confusion can be caused by the similarities of the terms 'mental health and psychosocial support', 'psychosocial wellbeing' and 'psychosocial disability', and due to some common outward symptoms and overlaps. Humanitarian health staff may wrongly attribute the symptoms of cognitive and psychosocial disabilities to post-traumatic stress caused by the humanitarian emergency, rather than an underlying neurological condition.<sup>92</sup>

Disability data should be routinely collected as part of disaster preparedness, and within the assessment and subsequent stages of humanitarian response. The Washington Group Questions will help to widen the limited evidence. The Washington Group Questions are designed to provide

comparable data cross-nationally for populations living in a variety of cultures with varying economic resources.

The Washington Group Short Set of Questions is designed for brevity and easy use in the field. It can elicit data on communication difficulties, self-care and remembering/concentrating. However it fails to fully capture the range of disabling symptoms of dementia that the Washington Group Extended Set of Questions provides. Capacity should therefore continue to be built among humanitarian actors to effectively use the Washington Group Extended Set of Questions which more effectively identifies those living with cognitive conditions like dementia.

The Age and Disability Capacity Building programme's Humanitarian Inclusion Standards use the Washington Group Questions and have significantly identified more people with disabilities than using existing data collection methods. When the UN Refugee Agency (UNHCR) piloted the Washington Group Questions in 98 registration interviews for the new entry of Syrian refugees in Jordan, the percentage of people identified as having disabilities increased 25 per cent from 2.36 per cent to more than 27.55 per cent.<sup>93</sup> UNHCR registration staff reported that the Washington Group Questions were useful in identifying 'hidden' disabilities, those that are not visible to the eye or self-reported by the interviewee. Moreover, the neutrality of the questions, and in particular avoidance of negatively-loaded terms, was also said to be useful to encourage disclosure of disabilities.<sup>94</sup> Use of the Washington Group Extended Set of Questions could be a potentially effective method of uncovering those living with dementia. Further piloting in communities where there is a high level of stigma around dementia would be useful.

Without identifying and consulting with people living with dementia, humanitarian actors are ill equipped to address their specific needs, or to design and implement inclusive projects. Data collection processes and systems must capture the multiple dimensions of people's lives. Data should not only be disaggregated by sex, age and whether or not someone has a disability; the nature of their disability should also be recorded and addressed to provide a more accurate picture of the affected population.<sup>95</sup> This will help identify people with greater support needs and those at greater risk of exclusion from humanitarian aid and services.

Knowing the numbers of people living with dementia, humanitarian actors are also able to make a stronger case for funding for specific and inclusive programming, closing the growing gap between funding and needs.<sup>96</sup>

As the seventh leading cause of death worldwide, humanitarian actors must recognise that in any given emergency there will be people affected by dementia, even if this is not immediately apparent. Therefore provision must be made for this population and support cannot wait for the collection of data to demonstrate the need for action.

Case study:

### Civil society leadership in Pakistan emergency response

The 2005 Pakistan earthquake, reaching a magnitude of 7.6 on the Richter scale, caused more than 100,000 deaths, left 200,000 injured and 3.5 million people homeless. In 2010 Pakistan suffered its worst floods in recent history. At its peak the flood waters covered roughly one-fifth of the country. More than 20 million people were displaced, 1,985 people were killed and 12 million people's homes were damaged or destroyed.<sup>97</sup> In the relief efforts after these natural disasters, volunteers working with Alzheimer's Pakistan noticed that people living with dementia were not receiving proper care as their condition was misunderstood.

People living with dementia were invisible to those coordinating humanitarian aid, omitted from needs assessments, planning and delivery of humanitarian assistance, leaving them voiceless and excluded from relief coordination. People living with dementia were neglected in terms of their diet, medical aid and hygiene.

*“The experience in Pakistan and elsewhere during such disaster situations has shown that people with dementia suffer worst as they are not on the radar for the relief work although they are one of the most vulnerable groups in such situations. This highlights the need to raise the profile of people with dementia and bring together all the stakeholders for the required improvements in the policy and practice so that the much needed help is provided to people with dementia during any future emergency situations.”*

**Dr Yasmin Rashid – Health Minister, Punjab, Pakistan; Patron of Alzheimer's Pakistan; and Former Board Member, ADI**

In response, during the massive earthquake, Alzheimer's Pakistan launched a campaign to help those living with dementia access the assistance they needed. An appeal to Alzheimer's Disease International for support was answered by national associations and individuals. Alzheimer's Pakistan worked in collaboration with a local NGO, Jahadad Society for Community Development (JSCD), which is one of the leading NGO's providing relief during emergency situations in the country. These efforts resulted in the much-needed relief for the people with dementia, who were identified, rescued and settled in a tent village with their families. The camp village established by Alzheimer's Pakistan and JSCD finally comprised of 300 tents having more than 2,500 affected people at the destroyed city of Balakot for the next eight months period. There they were provided with food rations, bedding, shelter and the required medicines.<sup>98</sup> A mobile medical clinic was also established for those people with dementia, who could not move to the tent village but needed medical help at different remote areas.



Dr Yasmin Rashid conducting a medical clinic for people with dementia in the camp during floods. © Hussain Jafri

*“During my experience of working in a number of different emergency situations, I have realised that not only my country but the world at large have become very vulnerable and are constantly being challenged by both the natural and manmade disasters. Survival of the fittest is the call of the day and people with dementia are often not only neglected, but their situation even gets worse as in most cases they require specialised care and often there is no one to care for them during disasters.*

*I felt there is a desperate need for improved awareness especially amongst the humanitarian actors about the plight and needs of people with dementia in emergencies, capacity building of people working in such situations especially the health care personals and the development of a comprehensive framework of action for humanitarian actors to follow for providing assistance and help to people with dementia in emergencies at all levels of care.”*

**Dr Hussain Jafri – Secretary General, Alzheimer's Pakistan**

Hussain Jafri has been driving efforts to continue this work and develop disaster preparedness processes. Alzheimer's Pakistan is a partner in the production of this report, working with the GADAA network, ADI and humanitarian partners to tackle this issue and raise the profile of dementia in the humanitarian response.



Pakistan special relief camp, comprised of 300 tents housing more than 2,500 affected people, after the earthquake destroyed the city of Balakot. © Hussain Jafri

Case study:

**Begum’s story – Cox’s Bazar, Bangladesh**

Sixty-seven year old Begum arrived at a camp in Cox’s Bazar, Bangladesh in November 2018 with her family.

*“I first met Begum after she met a health outreach team and informed them she was having memory and concentration problems but her family did not believe her. After an initial assessment and referral to a doctor, the team identified that Begum had signs of dementia and they worked with her family to help them understand dementia and how they can support her. Initially when the outreach team first met the family, they said that there had been family arguments for five to six years about meals, money and other things. We talked to the family about what dementia is and explained the symptoms.*

*On my second visit to the family they were much more positive. They said that they realised the family arguments were because of a lack of understanding that Begum had dementia. They now stopped blaming her for the things she was saying or doing as they understood it was the dementia and not her being unreasonable. Begum’s family said that no one had told them before what dementia was or why she was acting in certain ways. This case highlights just how important dementia awareness is.”*

**Dr Juma Khudonazarov – former Global Advisor, Humanitarian Health and Care, HelpAge International**



Age International’s age-friendly space in Balukhali camp, Cox’s Bazar, where older persons receive psychosocial support and medical care. © DEC/Barney Guiton

**Reduced mobility**

The later stages of the condition can have a big physical impact on a person’s mobility. People living with dementia in the later stage may lose their ability to walk or stand at all.<sup>99</sup> The brain may no longer be able to control the body as effectively due to related conditions such as apraxia and stiffness. These changes usually lead to someone moving more slowly, with less coordination and finding it harder to keep their balance, making falls more likely. Falls can lead to serious injury in older people living with dementia, as bones may break more easily and injuries can take longer to heal.<sup>100</sup>

*“I told them to leave me in the bush and continue to the secure area without me. They just cried. They told me that the strategy used to find people was to set fire to the forests. They said, ‘Don’t you see that you could burn?’ They decided to bring me to this secure area.”*

**Female with a physical disability, 62 years of age (HelpAge International, research from Tanzania)<sup>101</sup>**

People living with dementia, like other disabilities, can experience increased problems due to separation from family, loss of assistive and mobility devices, and difficulties with accessing information.<sup>102</sup> Those with reduced mobility, especially those with physical disabilities, need interventions to support them being evacuated from emergency settings.<sup>103</sup>

**Reduced capacity**

Those with dementia can have atypical reactions to crises and so may need extra support and guidance to prepare for, protect themselves and recover from emergency situations. Like others with cognitive and psychosocial disabilities, some people with dementia may resist leaving dangerous environments if they do not comprehend the threat that they face.<sup>104</sup> Similarly older people who have lived in a community for a long time may be less likely to leave their homes due to lack of resources to leave, restricted movement due to a disability, or because they feel they have nowhere else to go.<sup>105</sup> Those living with dementia may also perceive barriers to leaving or coping with an emergency situation as too great and so decide to remain.

Many people living with dementia will experience their cognitive abilities decline and this affects their ability to make decisions in difficult situations.<sup>106</sup> Visual and other sensory disabilities can prevent people from accessing or understanding information about available assistance and services.<sup>107</sup> Anecdotal evidence from 2012’s Hurricane Katrina supports the concern that people with advanced dementia may ‘disengage’ with the consequences of an emergency.<sup>108</sup> Humanitarian emergency evacuation strategies should consider the decision-making process for those affected by dementia, as well as the physical barriers to leaving.

### Disruption of routine/day-to-day tasks

As a result of dementia, day-to-day tasks become challenging. The person may start to lose track of time, where to find things, or have difficulty recognising people. During the disruption of a humanitarian emergency these tasks and actions can become even more difficult. For example, persons with dementia might not understand the adequate procedures for collecting food and drinking water if signage or information is not provided and maintained in formats accessible to them, or if additional support is not provided.

In the later stages of the condition, people with dementia may have additional continence needs, requiring safe and dignified access to sanitation facilities. To address these needs, people with dementia, alongside older persons with disabilities, must be included in water, sanitation and hygiene (WASH) assessments and monitoring activities.

### Changing dynamics of family and society

During humanitarian emergencies, people living with dementia can face heightened risks due to displacement and the breakdown of normal protection structures and support. Families often become separated from one another in crises. Older people and people with disabilities who are physically unable to flee can be left behind. Individuals with reduced mobility or eyesight are at particular risk of being separated from immediate family (or care supporters) in a disaster. Consequently finding foods they can easily eat, carrying bags or baskets, or cooking and cleaning may become unmanageable tasks.<sup>109</sup>

As a higher proportion of people living with dementia is older, it is important to note that as communities and power and support structures are dismantled, the traditional roles of older people, and perhaps more specifically their social position, change. This leaves older people with less influence and power.<sup>110</sup> The disruption and breakdown of normal family and community support structures can leave older people and those living with dementia isolated. This makes it hard for them to access the services and assistance they need.<sup>111</sup>

The families of those living with dementia can be faced with a stark choice when disaster strikes. The physical and psychological barriers, or perception of barriers, may lead those in a dementia care support role to make choices they would not consider in normal circumstances. For instance, sending ageing family members to a retirement home was not a cultural norm in Syria. However, after years of war and displacement, many families feel they have little choice. In 2016, as the conflict claimed the lives of younger people, or forced them to relocate, older family members were increasingly being sent to oversubscribed care homes in safer regions.<sup>112</sup> The impact of conflict on the Syrian health workforce has been catastrophic. Health workers, caught up in the conflict themselves, may become internally displaced or forced to flee the country in fear of targeted attacks. Estimates suggest that up to 27,000, or over half of all Syrian doctors, have fled the country since 2011.<sup>113</sup>

After an initial emergency response, younger people may still choose to move away from an area hit by a crisis; infrastructural breakdown is likely to reduce opportunities. This exodus can lead to challenges in building the health and social care workforce, as well as diminishing family support.<sup>114</sup> In low- and middle-income countries, women are more likely to stay behind during conflict or a natural disaster to care for children and look after family members, while male family members leave the area in search of work.<sup>115</sup>

Dementia even in normal times puts incredible strain on families who need instruction in how to provide basic nursing care as the disease progresses. Being able to access respite and palliative care services can make the difference in whether the family can continue to provide care rather than abandoning or placing the person living with dementia in an institutional setting.

There is a lack of access to the first-hand experiences of those living with dementia who stay, or are left, behind in crises. This makes it difficult to establish the exact causes and consequences. Much more research is needed in this area to definitively ascertain how and why people living with dementia are left behind in humanitarian emergencies, and the extent of the issue.

## 2.2 Health and care needs

When it comes to public health programmes in humanitarian emergencies, aid organisations tend to focus on infectious disease outbreaks. Non-communicable diseases (NCDs), including dementia, are usually not considered a priority.<sup>116</sup> This section explores how inadequate health programmes, and lack of continuous and accessible healthcare impacts people living with dementia during humanitarian response.

*“I met an older woman from Afghanistan living with her family in a makeshift camp outside Athens, Greece, in December, 2016. She told me about getting lost, and (speaking through a translator) said, ‘I think I have Alzheimer’s because my daughters say I forget a lot and a doctor told me so. I ask questions again and again. The [camp] doctor cannot understand my problems. He told me I need to go to the hospital. He said a paper explains how to go to the hospital. The referral form from the doctor was written in English and Greek. It did not say which hospital’.”*

**Bethany Brown – Researcher on Older People’s Rights, Human Rights Watch**

Case study:

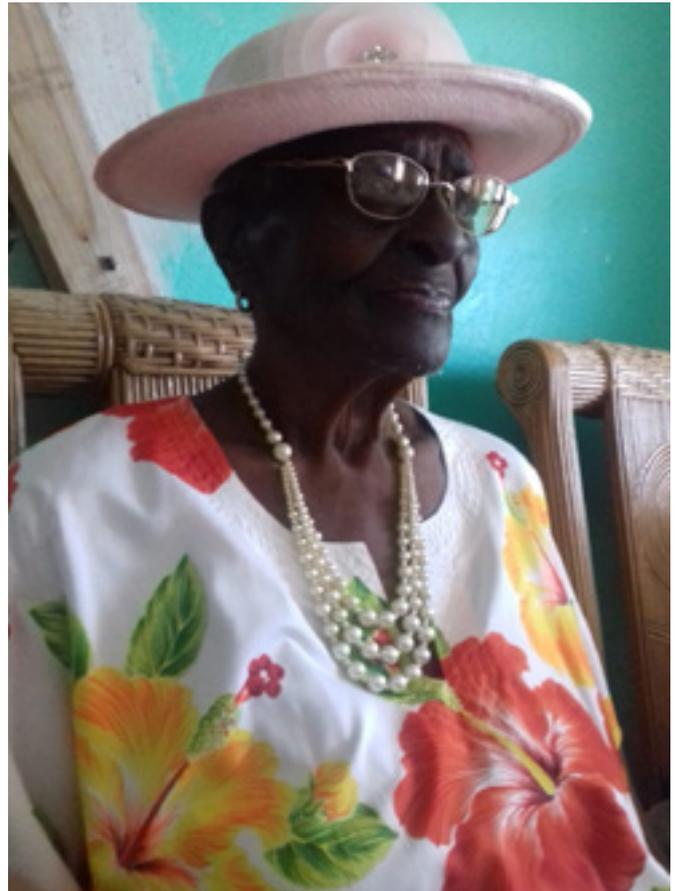
### Constantia's story – Hurricane Irma, Sint Maarten

In September 2017, Hurricane Irma impacted the lives of many in the Caribbean and Sint Maarten received a direct hit. According to the Sint Maarten Alzheimer Foundation, the hurricane affected not only the approximately 73,000 registered inhabitants on the island (41,000 on the Southern side under Dutch administration and 32,000 on the Northern side under French administration), but also an estimated 20,000 non-registered undocumented persons on the island, as well as over 2,000 stay-over tourists. On the Southern part under Dutch administration more than 70–80 per cent of the homes were structurally damaged.

Constantia was scared during the passing of the hurricane. She is an 84-year-old lady living with undiagnosed dementia. She lives in her home in St Peters near two of her daughters, Patsy and Gale, who live with their families in adjacent dwellings in the same yard. The day the hurricane arrived it was difficult for Gale to leave her apartment to go to stay with her mother because the wind was so strong. Constantia was relieved to see Gale. They went into the bathroom to hide during the first part of the storm. Constantia was sitting down and looking up. When the roof was blown away they could see the sky. When the eye of the hurricane passed, they managed to get to Patsy's house to sit out the tail of the hurricane.

Gale said, *"We had to climb over zinc, debris and nails to get at my sister's apartment. We were just inside when the hurricane started again. Thank God it was moving fast. Mom still wanted to go back in her house. We stayed with seven persons in one bedroom for days in the apartment of my sister Patsy. We could not sleep because mom was crying the whole night 'I have to go home'."*

After the hurricane the situation of abnormality worsened the condition of Constantia's dementia. It was difficult to make the home comfortable for Constantia. Everything was still in boxes and covered under tarpaulin and for months after the hurricane they were still waiting for help to repair the roof. Constantia became depressed because of the damage to the home that she had built. She felt scared and cried a lot, saying *"this hurricane was really bad"*. She did not want to eat, even with the support of her daughter Gale who was her main care supporter. She started to forget to go to the bathroom and she would start cursing when Gale wanted to help her to go. She found it difficult to understand the time of day, for example taking a shower in the afternoon, or thinking evening was coming at 3pm. Confusion had kicked in.



Constantia at home. © Gale Hodge

Constantia went to live with her third daughter but when away from her house she worried people might steal from it. She would sneak away, walking in the hot sun to go to her home. On one occasion Gale found Constantia sleeping on the ground. When asked why, Constantia answered *"in case hurricane come"*.

When Gale went to live with other relatives, she visited her mother every day. Fighting back her own tears, Gale recalls this period: *"She was crying almost every day when I had to move to Cole Bay. She would forget when I came, and she told me she thought I'd given up on her, and she would cry and hold me so tight like she did not want to let go"*.

Constantia was happy when in January 2018 a tourist came and in just one week built her a new roof – she was able to return home.

Case study:

### Utilising civil society expertise in Iran

In November 2017, in the wake of an earthquake in the West of Iran, representatives from 20 Iranian NGOs working on health and social issues joined forces to discuss how to address health challenges arising from the crisis. They formed a Humanitarian Crisis Committee including the Iran Dementia and Alzheimer's Association which represents people affected by dementia. The organisations decided to set up a 'Health Headquarters' at the Kermanshah University of Medical Sciences, to address the earthquake crisis response.

The headquarters worked in consultation with local authorities and in coordination with the Ministry of Health. Five representatives of NGOs from the headquarters worked with the affected population to address their needs.

They identified problems and worked closely with the headquarters to find solutions. They coordinated the appropriate responses in the affected areas reaching out to the people under their care, considering the short-, intermediate- and long-term responses needed to ensure health coverage for the required services. To date the Humanitarian Crisis Committee's work is still ongoing. In 2018, an Alzheimer's association was established in the Kermanshah region, making it much easier to follow the progress of people living with dementia that were helped during the 2017 response. Using this information, the association has also started to develop a database identifying future needs.

### Inadequate healthcare

Humanitarian disasters cause disruption to existing health and care resources and impair the capacity of services to meet specific needs of persons affected, due to the break down in authority, healthcare systems and societal cohesiveness.<sup>117</sup>

While the impact of non-communicable diseases (NCDs) on the health of populations, health systems and socio-economic development is well known, their importance in humanitarian emergencies has not yet been fully recognised.<sup>118</sup> In older age, many people have one or more chronic NCD. In low- and middle-income countries, older people are especially at risk, due to the lack of available public health services and infrastructure. Non-communicable diseases such as cardiovascular disease, cancer, stroke, diabetes and dementia are common.<sup>119</sup> Almost three quarters of all NCD deaths (28 million people) occur in low- and middle-income countries.<sup>120</sup> In fact, the majority of people living with dementia live in low- and middle-income countries where humanitarian emergencies are more widespread.<sup>121</sup>

In the immediate aftermath of an emergency, the priority of humanitarian actors is to minimise mortality, typically focusing on treating life-threatening or acute severely symptomatic conditions.<sup>122</sup> Relief workers frequently look for signs of outward distress and physical medical needs, neglecting equally acute, but often less visible, chronic conditions and those with cognitive or psychosocial disabilities.

Dementia in its later stages is also associated with high levels of morbidity. Yet people living with dementia are less likely to be diagnosed for comorbid health conditions (which, when left untreated, can cause faster decline) and to receive the care and support they need to manage them.<sup>123</sup>

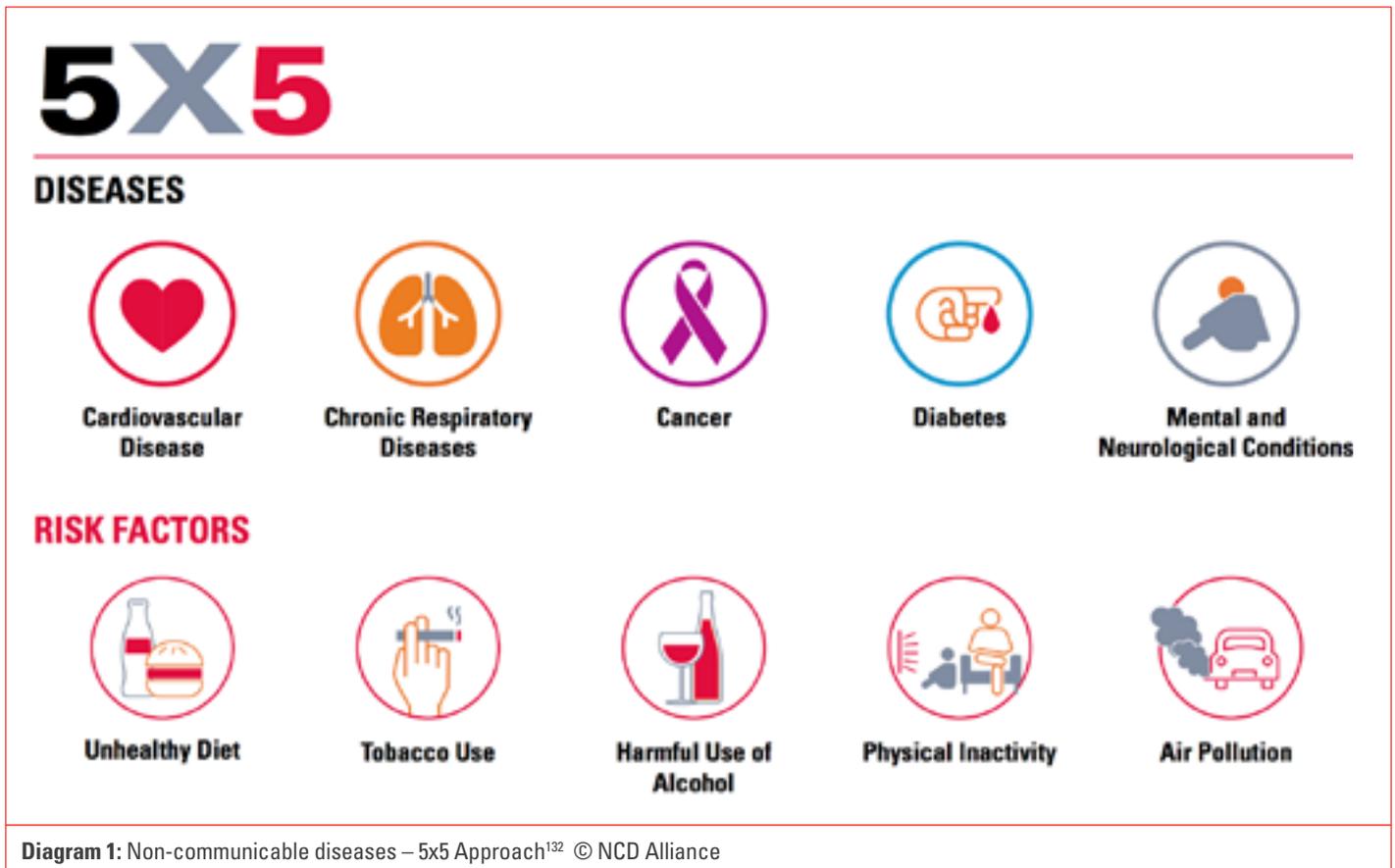
Early in a response effort, populations may not receive continuity of treatment for chronic conditions such as dementia. However, people caught up in humanitarian emergencies die or experience increased disability as a result of previously manageable chronic illnesses deteriorating and a lack of access to regular healthcare

and medication. Médecins Sans Frontières has identified those with NCDs as the 'silent casualties' of war.<sup>124</sup>

A report of the WISH Healthcare in Conflict Settings Forum 2018 confirms that NCDs are a major and increasing cause of morbidity and mortality in areas of protracted and recurrent crises.<sup>125</sup> For refugees, the cost of NCD care falls on host countries; for example, the Jordanian Ministry of Health spent \$53 million on care for refugees over just three months in 2013.<sup>126</sup> Only modest help has been provided through international aid to expand host country health capacities, with even less available for NCD care.<sup>127</sup>

Data indicating which NCD interventions in humanitarian response have the best outcomes, and how to deliver them, are limited.<sup>128</sup> In Syria, research has found that challenges to NCD care implementation included a lack of knowledge on unmet needs in the population, lack of consensus on healthcare provision objectives, and no clear methodology for prioritising resources.<sup>129</sup> In 2018 a qualitative study was undertaken with humanitarian health staff working on NCD healthcare in Syria. It demonstrated a lack of understanding of the population need for NCD care and health staff reported a lack of population level data. Interviews revealed disagreement about how to allocate resources among different health services, especially between care for war trauma and other urgent cases, versus treatment for chronic disease.<sup>130</sup>

When NCDs in humanitarian programmes are funded and delivered, typically only what was known as the 'big four' (cardiovascular diseases, cancers, chronic respiratory diseases and diabetes) have received attention. At the 2018 third High-level Meeting (HLM3) on the prevention and control of non-communicable diseases, member states adopted a Political Declaration which transforms the '4x4' into a '5x5 agenda'.<sup>131</sup> This refers to the five main NCDs and the five leading risk factors in common, officially adding mental health and neurological conditions within the five for the first time (see diagram 1). This definition change may help to increase awareness and understanding of dementia as a non-communicable disease, and therefore increase action.



The Sphere Handbook (2018) advises that when it is evident that a humanitarian response will last more than several months or years, humanitarian actors should consider different means of meeting needs and supporting life with dignity. It is recommended to explore opportunities to work with existing service providers, local authorities, local communities, social protection networks or development actors to help meet individuals’ needs. Further, long-term and permanent solutions should be pursued as early as possible and when humanitarian actors have the opportunity to establish durable solutions, those should take precedence over temporary measures.<sup>133</sup>

More can be done to provide training for humanitarian staff, to recognise the needs of people with dementia and other cognitive disabilities, and to understand and effectively implement guidelines and tools designed to serve them. Humanitarian actors must also seek advice and work in collaboration with existing dementia specialists, including health professionals, dementia organisations and people affected by dementia.

### Practical recommendation

- ☑ Identify dementia-specific healthcare and support needs, including the provision of information, medicines and assistive devices.

## Accessibility

Even where appropriate healthcare exists in humanitarian settings, those with dementia may be less mobile and unable to access these services. People living with dementia face unique challenges in accessing new health and care systems; staff might be unable to communicate effectively if they are not aware of dementia symptoms.<sup>134</sup>

There are various symptoms of dementia that present difficulties with accessibility, impacting diagnosis, treatment and informed consent. A person with dementia may have trouble finding the right word, they may repeat words and phrases, or may become 'stuck' on certain sounds. In addition, people living with dementia are likely to have other sensory impairments (such as sight or hearing problems) which can also make it harder to communicate. Vision and perception difficulties can lead to misperceptions (when a person sees one thing as something else, for example, mistaking a blue-coloured floor as water) and misidentifications (for example mistaking a son for a husband or brother), leading to additional support needs.

As dementia progresses, people may only be able carry out simple activities, or not be able to concentrate for long periods. They may find themselves increasingly disorientated and have difficulties recognising where they are. They may have a limited understanding of time, which can result in missing medical appointments. Dementia is likely to have a significant physical impact on the person in the later stages of the condition. A person may gradually lose their ability to walk, stand, speak or get themselves up from the chair or bed. They may also be more likely to fall, making it harder to reach support services and leading to greater risk of physical injury. However, not all people living with dementia will have problems with mobility or accessibility.<sup>135</sup>

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## Practical recommendation

 To address some of the barriers in travelling to and accessing assistance, provide seating, shade, safe drinking water and toilets at distribution points.

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## Continuity of care

While dementia currently has no cure, treatments can slow down its progression and control some of its symptoms.<sup>136</sup> Degenerative conditions like dementia deteriorate more rapidly without routine assessment and treatment.<sup>137</sup> Dementia in particular requires continuous, coordinated care over an extended period including palliative care. Even during non-emergency situations, people living with dementia are frequently denied their human rights in both the community and formal care settings. People with dementia are frequently denied the basic rights and freedoms available to others.

In many countries, physical and pharmacological restraints are used extensively in care homes for older people and in acute-care settings, even when regulations are in place to uphold the rights of people to freedom and choice.<sup>138</sup> In addition, people living with dementia are not always involved in decision-making processes and their wishes and preferences for care are often not respected.<sup>139</sup>

During the disruption and chaos of an emergency situation, a person living with dementia may not be able to communicate or express their unmet healthcare and support needs. Those living with dementia who previously had access to healthcare may be at risk of their dementia symptoms being ignored or misdiagnosed due to limited awareness and expertise of humanitarian actors. Behavioural and psychological symptoms of dementia may be misunderstood as a response to the emergency situation. This can lead to health professionals prescribing medications for behaviours that frequently are a result of a person's response to unmet needs.<sup>140</sup> Unnecessary reliance on use of antipsychotic drugs for people living with dementia, can further disable people due to side effects. Persons with cognitive, intellectual or psychosocial disabilities also may not be asked for their consent before such treatment.

Ultimately those with dementia will require palliative care, another aspect of health in emergency settings that is frequently overlooked.<sup>141</sup> Dementia as a cause of death also requires access to palliative care services. A recent report estimates almost 1.9 million people with dementia needing palliative care globally including 618,000 at the end of life in 2015.<sup>142</sup>

When establishing dementia and other mental health and psychosocial specific health services in a humanitarian context, it is important to respect the principle of equity.<sup>143</sup> The 1951 Convention on the Status of Refugees states that refugees are entitled to health services equivalent to that of the host population, and that everyone has the right to the highest standards of physical and mental health.<sup>144</sup> It is important to recognise that in low- and middle-income countries resident or host populations should also have access to similar services humanitarian actors are providing to internally displaced persons and refugees.<sup>145</sup> More and more internally displaced persons and refugees are living in urban settings rather than in camps. As a result, existing health services face new pressures from the influx of new populations. To support, humanitarian actors need to adapt their traditional response in order to provide optimal interventions.<sup>146</sup> This requires humanitarian actors working with existing dementia specialists and organisations, DPOs and relevant government ministries to strengthen existing health systems, with additional training and funding for material resources and staff to increase their capacity.

Case study:

### **Puerto Rico's older people go without humanitarian assistance<sup>147</sup>**

The humanitarian crisis unleashed by Hurricane Maria in September 2017 affected all 3.5 million people on the island. Puerto Rico's power grid was taken down by the storm and the health system decimated. Two weeks after the hurricane hit, humanitarian assistance had still not reached some of Puerto Rico's most vulnerable citizens.

*"Many elderly people including people with dementia, died as consequence of the lack of food, health services or transportation,"* says Ana L Gratacos, President of the Asociación de Alzheimer de Puerto Rico.

*"The husband of one of the members of our board of directors, died of complications from Alzheimer's disease, directly related because of the lack of health services in her community after Hurricane Maria."*

Ana L Gratacos reports that humanitarian actors were unable to provide assistance specifically to help people affected by dementia escape during the emergency. In addition, shelters without trained personnel in dementia care compounded the problem.

*"The psychological consequences of the loss of lives were devastating"* for the care supporters of people living with dementia, says Ana L Gratacos. She also reports that due to a lack of health and care support for people with dementia, many people left the island to seek assistance in the United States.

Luis Vega Ramos, a member of the House of Representatives in Puerto Rico, coordinated a group of volunteers during the humanitarian response. For forty to fifty days after the hurricane hit, Luis and a few others coordinated the work of up to sixty volunteers, meeting at around 7am every day. The group of volunteers included a diverse group of students, engineers, health professionals, social workers and psychologists. In the first ten days after Maria hit, they made more than twenty trips to retirement homes and sheltered housing. For people living with dementia and those who support them, *"the impact [of the hurricane] was severe"*.



Las Teresas retirement apartments during Hurricane Maria, Puerto Rico in 2017 © REUTERS/Carlos Barria



Luis Vega Ramos and Ana L Gratacos © Cromance Foto

At Las Teresas retirement community, consisting of two apartment buildings for people over the age of 62, residents were found dehydrated, without food and low on medical supplies including oxygen tanks. Volunteers visiting the retirement community, on the outskirts of the capital San Juan, found residents of the 15 story buildings had no electricity for lighting and elevators didn't work. *"You had elderly people, some of them with mental health conditions stuck on the 12th, 13th, 14th floor who were accumulating trash, who had no refrigeration for some of their medicines, or their food"* said Luis.

*"It was very tough for the first couple of weeks. We were scared we could lose many of them through various health issues. Even though I didn't witness anyone losing their lives in those conditions, I am aware that in some instances sadly enough some people lost their lives because they didn't have the very essentials to survive."*

Luis worked throughout San Juan and reflects that in many cases family members assumed that institutions would take care of their elderly relatives during the crisis. *"It was sad to talk with many of the elderly people, some of them with dementia and other mental conditions and when you asked them about their family members – had they come, had they brought them something, had they taken care of their medication – in too many cases sadly some of those family members were lacking or absent."*

To improve emergency response planning, Asociación de Alzheimer de Puerto Rico is working with the government to develop a mitigation plan. The Association believes that training government personnel will also improve coordination. It started to provide such training in September 2018 with the Puerto Rico Department of Family Affairs. Ana L Gratacos says that *"by creating protocols in businesses, government departments, schools, universities, churches, community centres and mass media education"* awareness will improve the preparedness and support for people affected by dementia in humanitarian emergencies.

**Diagnosis and assessment**

Many humanitarian actors are unaware of dementia in the context of an emergency, particularly of how to make a diagnosis or the tools available (for example WHO’s mhGAP Intervention Guide, discussed further in chapter 4).<sup>148</sup> Older persons may not receive a diagnosis of dementia as it is commonly misunderstood as an inevitable part of ageing. Dementia is also associated with high levels of morbidity in later stages, yet people living with dementia are less likely to be diagnosed for comorbid health conditions (which, when left untreated, can cause faster decline and disability) and less likely to receive the care and support they need to manage them.<sup>149</sup>

In the course of this research, HelpAge (an international organisation working on the rights of older persons), was the only organisation to report routine identification of those living with dementia as part of their wider health checks in humanitarian response (see ‘Assessing for dementia in humanitarian settings’ below). WHO sets a target for 50 per cent of the estimated number of people living with dementia to be diagnosed in at

least 50 per cent of member states by 2025.<sup>150</sup> Even where diagnosis is established in pre-emergency settings, there is still a critical need for improved diagnosis worldwide.

In low- and middle-income countries up to 90 per cent of people living with dementia remain undiagnosed, and so miss out on medical or social support.<sup>151</sup> With proper awareness in place, emergency and post-disaster settings could provide an opportunity for identification of people living with dementia and introduction of support. Tools such as the Washington Group Extended Set of Questions and WHO’s mhGAP resources (see chapter 4) provide support to identify those with dementia and other cognitive disabilities. If humanitarian actors have medical knowledge of a condition that the affected population traditionally lack experience with, a relief response could actually improve health outcomes for so-called ‘invisible’ conditions like dementia. Building dementia awareness into disaster preparedness and risk reduction programmes could also mitigate the barriers to accessing care outlined above.

Case study:

**Assessing for dementia in humanitarian settings**

Needs Assessments are usually conducted in the early stages of an emergency, to identify the needs of the affected populations, such as shelter, health, sanitation and food needs.<sup>152</sup> A coordinated approach to assessments involves humanitarian actors (and development actors where possible), to plan and carry out needs assessments to avoid duplication, reduce gaps and obtain a stronger overall vision of the crisis.<sup>153</sup> Conducting needs assessments is an opportunity to identify people living with dementia, including identifying those that are living with symptoms but have yet to receive a diagnosis and support.

Humanitarian actors use a range of tools and guidance to support the delivery of needs assessments, strategic planning and system-wide monitoring. HelpAge International’s Rapid Assessment Method for Older Persons (RAM-OP) is a practical and simple-to-use tool for identifying persons with specific needs, including those showing symptoms of dementia.<sup>154</sup>

Following an initial Rapid Needs Assessment to establish urgent needs older people, RAM-OP can be used to unpack further the challenges older people are facing in relation to health and nutrition. While the initial Rapid Needs Assessment uses the Washington Group Questions to identify people with a disability, the RAM-OP indicator questions ask a range of simple questions including some to test short- and long-term memory. Volunteers and staff can collect data offline using a digital application to record answers to the questions, an app then analyses the data and records it on a central system, providing live data for monitoring purposes.

Use of the RAM-OP assessment in HelpAge programmes in Bangladesh showed 49 per cent (of 1,335) older people have moderate or severe memory and concentration problems. In Borena, Ethiopia 22.5 per cent (19.8 per cent male and 25 per cent female) were reported to have signs of dementia. In Kenya 15 per cent were identified with probable dementia with a higher prevalence (8 per cent higher) among older men.<sup>155</sup>

**Dementia screen**

<p><b>da1</b> This section can only be completed if the subject is answering for themselves.</p> <p>If the respondent is not answering for themselves then record 'N' as the answer for all questions below and continue with the interview. Write the reason why the subject is not answering for themselves in the OBSERVATIONS section at the end of the questionnaire.</p> <p>Say: I am going to tell you three words. I would like you to repeat them after me.</p> <p>"CHILD" "HOUSE" "ROAD"</p> <p>Repeat the three words, up to a maximum of six (6) times, or until the person has remembered them all correctly.</p> <p>Say: Try to remember these words. I will ask about them later.</p>		<p>1 = Correct 2 = Incorrect # = Not applicable</p>	<input type="checkbox"/>
<b>da2</b>	Point to your nose and ask: What do we call this?	1 = Correct 2 = Incorrect # = Not applicable	<input type="checkbox"/>
<b>da3</b>	What do you do with a hammer? Accept answers such as: Drive a nail into something; Straighten metal; Hit a wedge or something else; Use with a chisel.	1 = Correct 2 = Incorrect # = Not applicable	<input type="checkbox"/>
<b>da4</b>	What day of the week is it?	1 = Correct 2 = Incorrect # = Not applicable	<input type="checkbox"/>
<b>da5</b>	What is the season?	1 = Correct 2 = Incorrect # = Not applicable	<input type="checkbox"/>
<b>da6</b>	Say: Please point first to the window and then to the door.	1 = Correct 2 = Incorrect # = Not applicable	<input type="checkbox"/>
<b>da7</b>	Do you remember the three words I asked you to remember a few minutes ago?		
<b>da7a</b>	CHILD	1 = Correct 2 = Incorrect # = Not applicable	<input type="checkbox"/>
<b>da7b</b>	HOUSE	1 = Correct 2 = Incorrect # = Not applicable	<input type="checkbox"/>
<b>da7c</b>	ROAD	1 = Correct 2 = Incorrect # = Not applicable	<input type="checkbox"/>

HelpAge International’s RAM-OP questions test short- and long-term memory to identify dementia.<sup>156</sup> © HelpAge International

It is important to recognise that people’s needs change throughout a humanitarian response and needs assessments must be used to enable humanitarian actors to adapt assistance, based on the changing needs of affected populations. This is especially important for people living with dementia or showing symptoms of the condition, as their physical and psychosocial needs will change as the condition progresses and severity increases.

Humanitarian actors should not just rely on rapid needs assessments for gathering information on the scale of the need for dementia-specific needs, but acknowledge that in all communities there will be people living with dementia. Primary data of the pre-emergency situation should provide information on the scale of specific needs. Where unreliable pre-emergency data is only available, a primary healthcare approach should be adopted which takes into account public projections using national data of how many would be expected to live with dementia in any given population.

## 2.3 Food insecurity and malnutrition

*“The soldiers one day they were giving out water, another day they distributed food. You would not know when they are giving out what. We had to line up in the hot sun. They did not want to give me provisions for my elderly mom, they said I had to bring her for her to get. Elderly persons should not be treated like that.”*

**Gale, whose mother lives with dementia, Sint Maarten, in the aftermath of Hurricane Irma, 2017**

Even if people living with dementia are able to escape the area of an emergency crisis, they may then be left to fend for themselves in unfamiliar relief camps.<sup>157</sup> Food insecurity and malnutrition has a severe impact on disabled and older people, as they face greater physical obstacles in accessing assistance.<sup>158</sup> Micronutrient deficiencies have severe consequences for older people’s mental and physical health, their immune system and their functional abilities. This can impair survival and recovery from crisis.<sup>159</sup>

It is therefore essential that the links between malnutrition and dementia, as well as nutritional needs of older people and those with other cognitive or psychosocial disabilities, are understood by those providing food supplies. Markets or food distribution points can be difficult for people with disabilities to reach and food aid packages do not routinely cater for older people’s particular nutritional requirements. However, the biggest challenge is that older men and women are rarely included in nutrition needs assessments and programmes,<sup>160</sup> which instead focus on children and pregnant and lactating women. This is despite a growing body of evidence on older people’s nutritional needs in emergencies.<sup>161</sup> This section looks at the importance of people living with dementia receiving and being able to access the right types of food.

*“It’s difficult for me to carry my food ration because of my poor health and my disabilities.”*

**Female, 100 years of age (HelpAge International, research from Tanzania and Ukraine)<sup>162</sup>**

### Malnutrition<sup>i</sup> for people living with dementia

In older age, both the quality and the quantity of the diet are important to ensure that requirements for macronutrient and micronutrient intake are met. Adults with reduced appetite due to illness, age, cognitive or physical disability often face a range of nutritional risks that can be further exacerbated in an emergency. This may lead to an inadequate energy and micronutrient intake at a time when the body needs it most.<sup>163</sup> For example, tooth loss, gum disease and difficulties chewing and swallowing have serious nutritional consequences as less, or more limited selections of food are taken.<sup>164</sup> Despite their specific need being generally known by humanitarian actors, older people are rarely included in nutritional needs assessments and interventions.<sup>165</sup>

As the human body ages, our composition of fat and muscle changes, influenced by modified hormonal activity. There is a progressive loss of muscle and an increase in fat stores. With muscle loss, people’s ability to move and maintain balance is affected, making falls more likely, and limiting the ability to collect and carry food aid rations and drinking water. Food aid rations can be too heavy to carry, and packaging too difficult to open for those with cognitive or physical impairments. Many older people report being pushed out of the way by more able-bodied people in the queue for aid.<sup>166</sup>

*“When I try to collect her portion they always tell me that I’m going to steal the food. They refuse to give me her portion.”*

**Family member (HelpAge International, research from Tanzania and Ukraine)<sup>167</sup>**

These issues also apply to people in the advanced stages of dementia, the majority of whom will be older. Those with dementia may need assistance with collecting food aid rations, food timing and reminders of when and what to eat, in contrast with others affected by emergencies. A 2015 Turkish study found that advanced dementia stage was independently associated with malnutrition.<sup>168</sup> While not concerned with a humanitarian emergency, this research also showed that malnutrition in those with dementia also seemed to be associated with sleep disturbances, psychological needs, immobility, falls and increased risk of hospitalisation.

<sup>i</sup> Malnutrition is a physiological condition caused by inadequate, unbalanced or excessive consumption of macro and/or micronutrients. It includes undernutrition and over nutrition as well as micronutrient deficiencies. Older people need specific micronutrients, protein and food that is easy to swallow and digest. See: <https://www.ageinternational.org.uk/policy-and-research/humanitarian-relief/older-people-in-emergencies/>

Assessment, analysis and planning also needs to carefully identify assisted eating needs and preparation support for the type of food required (for example liquid form) to make sure they are in line with nutritional needs.

### Practical recommendation

 **Humanitarian actors need to carefully assess the nutritional needs of persons with cognitive disabilities and chronic conditions in relation to, for example, micronutritional needs, quality of proteins and the content of other nutrients, as well as processed food.**

### Dementia caused by malnutrition

Nutritional disorders such as pellagra, caused by vitamin deficiency, can result in temporary cognitive impairment, with symptoms similar to dementia. Pellagra is a multi-vitamin deficiency disease associated with diets providing low levels of niacin and/or tryptophan and often other B vitamins. It results in changes in the skin, gastrointestinal tract, and nervous system. Symptoms appear as dermatitis, diarrhoea and dementia and can lead to death, if not treated.<sup>169</sup>

During famines or for refugees, populations need a balanced diet with adequate micronutrient intake. During the 1990s thousands of cases of pellagra occurred in refugee camps across the world as a result of low-nutrient relief food.<sup>170</sup> Dementia caused by pellagra is usually quickly reversible using niacin supplements, however if left untreated it can become chronic.<sup>171</sup> In recent years humanitarian agencies have learnt to prevent outbreaks with food fortification and supplementation.<sup>172</sup> However, the link between proper nutrition and dementia should be kept in mind for those responding to disasters and in camp settings.

### Practical recommendation

 **Include nutrient-rich foods in food aid rations: general food rations are likely to be lacking in micronutrients, and should be complemented in order to be more balanced. Some locally sourced foods such as groundnuts are a good source of vitamin B3 to prevent pellagra. Other legumes are also rich in vitamin B complex and minerals.**<sup>173</sup>

## 2.4 Mental health consequences of emergencies and dementia

It is important to note that people with dementia have specific mental health and psychosocial support needs which should be addressed by humanitarian actors. As already stated, humanitarian health staff may wrongly attribute dementia to the mental health consequences of the humanitarian emergency rather than an underlying medical condition. Humanitarian emergencies can also have a direct impact on the mental health of people living with dementia and on those who develop the condition later in life.

### Mental health consequences of emergencies

The psychological toll of conflict, disaster and insecurity affect those already living with dementia. Research reveals high levels of anxiety, depression and PTSD among older people affected by humanitarian crises in Syria, Ukraine, South Sudan and Sudan.<sup>174</sup> The mental health consequences of the emergency could lead to a further deterioration of any pre-existing conditions like dementia. In Japan for example, people previously living well with dementia in Sendai City displayed more symptoms of anxiety, disorientation and trouble coping with daily life after the 2011 earthquake and tsunami.<sup>175</sup>

People living with dementia who have been through an experience earlier in life can relive these events in great vividness and with intense emotional impact. Those with dementia may relive painful memories in a more literal way than others; they may feel they are living in a dangerous time and place again, as a 'flashbulb memory', rather than observing the trauma as a past experience. Those with dementia may recall the painful subjective emotional experience without the objective context behind that memory.<sup>176</sup>

The mental health consequences of emergencies can clearly have fundamental implications for dementia services that use nostalgia and memory prompts as therapeutic tools. For this reason a person-centred approach is vital in therapies that use reminiscence.

#### Case study:

### Dementia and Syrian refugees in Jordan

New research is underway to increase understanding of the scope and scale of dementia risk as a result of forced migration. Led by Dr Tala Al-Rousan, the research takes a critical opportunity to explore dementia risk in Syrian refugees in Jordan and to compare cognitive performance among those living in refugee camps to those living within the host community.

Working alongside the Global Brain Health Institute and Jordanian health experts and research partners, Dr Al-Rousan and her team will identify the relationship between mental health conditions and cognitive impairment caused and triggered by the mental health consequences of forced migration. Generating evidence will shape public health and clinical interventions that can be tailored to respond to the needs of older persons, such as older migrants and refugees.

The research has the potential to inform humanitarian dementia care and policy in low- and middle-income countries, such as Jordan.

This research is one of the rare academic studies of dementia in humanitarian crises and much more funded research is needed in this area.

## Exposure to humanitarian crises and cognitive decline in later life

Further research is needed to explore hypotheses linking exposure to humanitarian emergencies and the development of dementia in later life. One study shows that cognitive decline and increased rates of dementia are visible among older people after disasters, including hurricanes in the United States.<sup>177</sup> A review from 2016 suggests that chronic stress and anxiety in any setting can damage areas of the brain involved in emotional responses, thinking and memory, leading to Alzheimer's disease.<sup>178</sup>

Case study:

### Past experiences and person-centred approaches

A 2002 study investigated a Canadian care home for older Jewish people where 50 per cent of residents with dementia were Holocaust survivors. For this group the loss of short-term memory took them, once again, to the death camps. One resident, Chaya always picked up leftover food wherever she found it, even from street floors. Care home staff, however, understood her behaviour as they knew her history. Chaya's one-year-old baby, Miriam, starved to death in the Kaunas ghetto, where her husband also died. Other residents of the care home exhibited the painful memories in different ways; some were terrified of showers; others found baths evoked Nazi hypothermia experiments or the disinfectant of death camps.

The care home found ways to adapt to help residents. Its dental clinic has no gas, no one queues up for medicine, staff do not use torches at night. Care home employees also keep alert for unreported illnesses, because in concentration camps those who fell sick were left to die, meaning residents can suppress health issues. While this care home is exemplary in how it deals with the mental health consequences of past experiences, there are countless other survivors of horrific experiences globally who do not receive such high standards of care. Humanitarian settings limit the extent a person-centred approach can be delivered.<sup>179</sup>

## 2.5 Social factors

### Social networks

Emergencies erode individual, family, community and societal protective supports that may normally be available to people affected by dementia. These changes increase the risks of new problems and amplify pre-existing issues. Times of crisis can reduce inter-personal resources and capacity to cope with challenging events.<sup>180</sup> Loss of family members, care partners and community ties can leave those with dementia without vital support networks. For many survivors, the most difficult aspect of a humanitarian emergency is coping with day-to-day life afterwards. Everyone with dementia requires different

levels of support, but as the condition progresses eventually those affected will be unable to care for themselves and need help with all aspects of daily life, making a loss of support potentially life changing.<sup>181</sup>

While there is a lack of research into the disruption of social networks for people living with dementia in humanitarian emergencies, parallels can be drawn from the case of immigration deportation programmes in the US. Older adults report losing a vital source of stability when a family member is deported. They lose transport, financial resources and emotional comfort, and may gain new responsibilities such as caring for grandchildren.<sup>182</sup> Humanitarian agencies sometimes run family reunification programmes, but concentrate on reuniting children and parents, neglecting the needs of people with age-related conditions like dementia who may require family support.<sup>183</sup> The loss of a familiar community as a result of an emergency can have a negative impact on those living with dementia. Interventions to promote informal socialising for those with dementia should be considered in the aftermath of a humanitarian crisis.<sup>184</sup>

## Practical recommendation

 Address physical barriers that can prevent people living with dementia from accessing opportunities to attend and participate in social and learning activities, including the creation of safe spaces.

### Relocation

Being away from familiar locations and routines can be especially difficult for people living with dementia.<sup>185</sup> A study into the aftermath of the 2011 Great East Japan Earthquake and Tsunami found that the severity of housing damage was significantly associated with cognitive decline for 3,566 survivors aged 65 years or older.<sup>186</sup> People relocated to temporary housing after their houses were destroyed or severely damaged had the highest levels of decline. Interestingly, the study points to a decrease in informal social interactions with friends and neighbours influencing the odds of cognitive decline after the disaster, more than the loss of family and friends.<sup>187</sup> An earlier study from the Japanese Kobe earthquake in 1995 revealed that for five survivors living with dementia, moving into their children's homes after the quake led to increased anxiety about their property.<sup>188</sup> In Japan, separate studies of people with Alzheimer's disease after the 2011 earthquake found that 86 per cent of individuals had long-term recollection of an earthquake, but may lose their ability to cope when forced to leave their homes.<sup>189</sup>

US research reveals the damaging effects of disaster-evacuation on care home residents who are cognitively impaired. A study commenced in the wake of Hurricane Katrina in 2005, in response to hurricane-related deaths of care home residents, and the steady increase in the number of care homes evacuating under storm threat. More than 21,000 residents living in 119 at risk care homes were observed over three years, between 2005 and 2008. The research found the harmful impact evacuation

can have on residents who were cognitively impaired. Within the first 30 days after Hurricane Gustav in 2008, care homes saw a 2.8 per cent increase in the number of deaths and a 3.9 per cent increase within 90 days, compared to the study's findings in the previous two years.

People with additional memory or cognition needs may struggle compared to others to adapt to life in a new country, culture or community. Learning new languages, customs, values, public systems and laws are often part of a relocation process. Longer term, people living with dementia in a new country or unfamiliar territory within the same country can come up against language barriers and culturally inappropriate dementia diagnosis and care.<sup>190</sup> Accurate recall of very specific details can be critical to the asylum process in some countries, especially if a claimant lacks official documents. As dementia can make recollection of facts such as time and place difficult, those supporting asylum-seekers need to be aware of the effect dementia could have.

Case study:

### Hurricane Irma – the importance of family support networks

Herman and Vivvet, who is living with dementia, left Sint Maarten in the aftermath of Hurricane Irma in 2017.

*“We took the decision to leave the island and to go back to Vivvet’s family in Guyana. What made us take this decision was the amount of destruction, no water, no lights. We recognised that it would be a long way to recovery. Medication for Vivvet was limited and Vivvet was not herself – trauma started to affect her. We wanted to make sure that Vivvet was comfortable. We strived to get her involved and be with us at all times, we recognised the situation and her condition. Going back to family was key for Vivvet to become herself again. She immediately and constantly felt at home.”*

**Herman, recalling the impact of Hurricane Irma on his wife Vivvet, aged 52.**



Vivvet with the St Maarten Alzheimer's Foundation team  
© Raymond Jessurun

### Stigma

Stigma related to dementia is universal. This can range from social isolation (being locked up at home, denied opportunities to participate) and lack of access to services (or documentation), to a culture of ostracism, aggression and even violence for people living with dementia in some countries. Symptoms of dementia can be perceived as signs of mental illness or linked to supernatural beliefs such as witchcraft and superstitions.<sup>191</sup> When a community believes itself to be under threat, people can also rely more heavily on supernatural explanations. UNHCR reports that ‘in societies in which the belief in witchcraft is entrenched, accusations of witchcraft and witch hunts will escalate if the community is under stress.’<sup>192</sup>

In the context of humanitarian emergencies, stigma may also stop those affected by dementia accessing life-saving shelter, food and medical help. In communities, persons with disabilities may be feared or viewed negatively, especially in areas that are not supported by humanitarian actors. Fears that persons with disabilities would contaminate water sources or that they would make the latrines dirty are frequently reported.<sup>193</sup> This can mean either a lack of access to WASH facilities or restricted use to anti-social hours.

*“Misconceptions of disability or older age can fuel negative attitudes and discrimination, which may encourage some to think that older people and people with disabilities are not a priority for help. Equally, over-protection may cause people to be kept at home for their safety or because their disability or age is considered to be a source of shame.”*

HelpAge International<sup>194</sup>

Case study:

### Culture, context and mental health of Rohingya refugees in Bangladesh

A challenge for health professionals working with displaced Rohingya populations in the camps in Cox's Bazar in Bangladesh, is that there is often no direct correlation between Western defined diagnostic categories and the Rohingya vocabulary. This can complicate communication between mental health practitioners and Rohingya living in the camps.<sup>195</sup>

In Rohingya culture mental health conditions are often attributed to malevolent spirits – jinn – or the ‘evil eye’. There is belief that the ‘evil eye’ can be inflicted upon a person when any human with malevolent intent or ‘ill will’ looks at them.<sup>196</sup> Traditional healers play an important role and are consulted for treatment. Anecdotal evidence from northern Rakhine State indicates that in the absence of formal mental health services, family members sometimes brought people who were perceived as ‘mad’ to medicine peddlers who provided them illicitly with fluphenazine injections (long acting antipsychotic medication).<sup>197</sup>

Emergencies can intensify the effects of stigma, such as resentment about perceived preferential treatment for those who are chronically ill. Professor Shuichi Awata of the Tokyo Metropolitan Institute of Gerontology reports that in the aftermath of the 2011 Great East Japan Earthquake, several nursing homes functioned as emergency shelters and effectively supported older people living with dementia. However excessive demand, staff shortages and increased responsibilities for remaining staff reduced the quality of care they were able to provide. There were reports that the new temporary inhabitants complained about the behaviours of the residents living with dementia. This lack of understanding and acceptance was exacerbated by the stressful context.<sup>198</sup> Dementia awareness as part of disaster preparedness strategies can be an effective mechanism to avoid this situation.

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### Practical recommendation

 **Humanitarian staff should adapt the language they use when talking about dementia, ensuring they use inclusive language and understand that some cultures do not even have a word for dementia.**

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### Discrimination and abuse

Safeguarding and protection policies and training for humanitarian staff should explicitly refer to the specific protection needs of people with all types of disability, including dementia.

The Humanitarian Principles – humanity, neutrality, impartiality and inclusion – at the heart of humanitarian response, should afford everyone the right to safe and dignified access to assistance and protection.<sup>199</sup> People with disabilities are at high risk of abuse during a humanitarian emergency. Discrimination based on disability, age and gender often combines with other forms of discrimination to deny older people and people with disabilities their right to assistance and participation in humanitarian action.<sup>200</sup>

When providing humanitarian assistance – whether it is rural, urban or camp settings – all aid agencies must take into account the local power dynamics, local authority structures and heterogeneity in community composition (for instance social class, ethnicity, locality of origin, age, gender and disability).<sup>201</sup> People living with dementia are typically not explicitly included in the publically available safeguarding and protection policies of major humanitarian agencies; meaning their specific protection needs could be overlooked in staff training, information and policy procedures.

In a 2015 Humanity and Inclusion investigation into the experience of disabled people in crisis, 27 per cent of respondents reported that they had been subject to physical, psychological or other type of abuse including sexual abuse. More than half of the internally displaced respondents (59 per cent) report having been subject to some form of abuse.<sup>202</sup> Respondents who had difficulties with their memory or concentration were particularly subject to abuse during a crisis.<sup>203</sup> These findings raise protection concerns for people living with dementia.

A contributing factor to this high level of abuse may be a lack of appropriate shelter for those in emergency settings who require special care. In 2015 the National Centre for Social Solidarity, a Greek non-governmental organisation (NGO), highlighted their concerns over a lack of appropriate shelter for asylum-seekers with dementia in the country.<sup>204</sup> Cycles of dependency, discrimination and isolation can put people living with dementia at risk of ill-treatment at the hands of family or community members. In the community, a perceived vulnerability of older people may result in violence and psychological distress<sup>205</sup> especially for those with dementia. Heightened levels of mistreatment may be due to dementia care partners' increased stress during humanitarian emergencies. As the behavioural symptoms of dementia can become more evident and exacerbated during a crisis, care partners may not feel able to cope or respond acceptably.<sup>206</sup>

Another factor to take into account when examining the link between dementia and abuse in humanitarian settings is the gender of those affected. More women than men live with dementia globally and the majority of dementia care partners are female.<sup>207</sup> All women face heightened risks in emergencies due to displacement and the breakdown of normal protection structures and support. More than 70 per cent of women have experienced gender-based violence in crisis settings.<sup>208</sup> Women also face increased care-related tasks such as providing food and water, and caring for ill community members. Studies have also found that due to women's societal roles as care-givers, during disasters they are more likely to make sacrifices, such as eating less food for the wellbeing of their families.<sup>209</sup> Women contribute to 71 per cent of the global hours of informal care, with the highest proportion in low income countries.<sup>210</sup> The annual global number of informal care hours provided to people with dementia living at home was about 82 billion hours in 2015, equating to 2,089 hours per year or 6 hours per day. This is the equivalent of more than 40 million full time workers in 2015, a figure that will increase to 65 million full time workers by 2030.<sup>211</sup>

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### Practical recommendation

 **In some communities, persons with disabilities like dementia may experience violence or abuse because they are feared or viewed negatively. Set up physical safe spaces for those with cognitive and psychosocial disabilities and those that support them.**

Case study:

### **Taking lessons from emergency services**

Having dementia-specific response plans for emergency organisations (such as ambulance, police and fire brigade services) is vital for the first stages of an emergency response for people living with dementia, if emergency services are still in action. Preparedness can include, for example, training of response staff to identify symptoms of dementia, resource planning for specific health and care needs, and dissemination of pre-emergency information. Lessons can also be learned from dementia-focused emergency service best practice and applied to humanitarian planning.

### **Lessons from the United Kingdom: Ambulance and police emergency training**

The Association of Ambulance Chief Executives provides a comprehensive response to assist those with dementia in medical emergencies.<sup>212</sup> Many local UK police forces have also developed their own training and resources on dementia, including adopting the Herbert Protocol.<sup>213</sup> The Protocol is a national scheme which encourages families or care partners to gather useful information which could be used in the event of a vulnerable person going missing. A form is completed to record details such as: medication, mobile numbers, routines; places an individual may have been found previously; and a recent photograph. If someone with dementia goes missing, the form can be used to reduce the time taken in gathering this information, and ultimately the time it takes to find someone who may have gone missing.

### **Lessons from the United States: Free first responder training**

The United States has a large ageing population, with a high proportion living in coastal regions, prone to hurricanes and flooding. Civil society and private sector organisations offer free first responder online training programmes to equip law enforcement, firefighters, medics, care partners and community members with information and protocols for emergency preparedness to help people living with dementia in a disaster.<sup>214</sup> The US Alzheimer's Association, RTI International and the US Administration on Ageing have also developed a disaster-preparedness toolkit for people living with dementia.<sup>215</sup> The *Disaster Preparedness: Home and Community-Based Services for People with Dementia and their Caregivers toolkit* demonstrates how disaster preparedness plays a critical role in reducing unnecessary institutional care. It summarises key actions, signposts resources, and guides state officials and care partners to engage in disaster preparedness.

# Relevant international standards and frameworks

In the last decade there has been an increase in global disability-inclusive commitments. Yet, more must be done to promote the full rights and dignity of people living with dementia and with other cognitive disabilities in humanitarian settings. This chapter explores and reviews some of the relevant international humanitarian standards and frameworks that offer protection for people living with disabilities, including their application to dementia.

## 3.1 The Core Humanitarian Standard on Quality and Accountability

The 2014 Core Humanitarian Standard on Quality and Accountability (CHS) describes the essential elements of principled, accountable and high-quality humanitarian action. Humanitarian organisations may use it as a voluntary code with which to align their own internal procedures. It can also be used as a basis for verification of performance by external donor agencies or governments. The CHS seeks to ensure greater consistency of humanitarian standards by all humanitarian actors. The CHS sets out the Nine Commitments to improve the quality, effectiveness and accountability of humanitarian assistance, see diagram 2 on page 30.

Under Commitment 1 of the CHS, organisations that adopt the standards are encouraged to design and implement appropriate programmes based on an impartial assessment of needs and risks, and an understanding of the vulnerability and capacities of the different groups, including 'women ... older persons, as well as persons with disabilities.' The CHS calls on humanitarian bodies to take action to prevent programmes having any negative effects; such as exploitation, abuse or discrimination by staff against communities and people affected by crisis (3.8). It also calls on bodies to have a code of conduct that establishes, at a minimum, the obligation of staff not to exploit, abuse or otherwise discriminate against people (8.7).

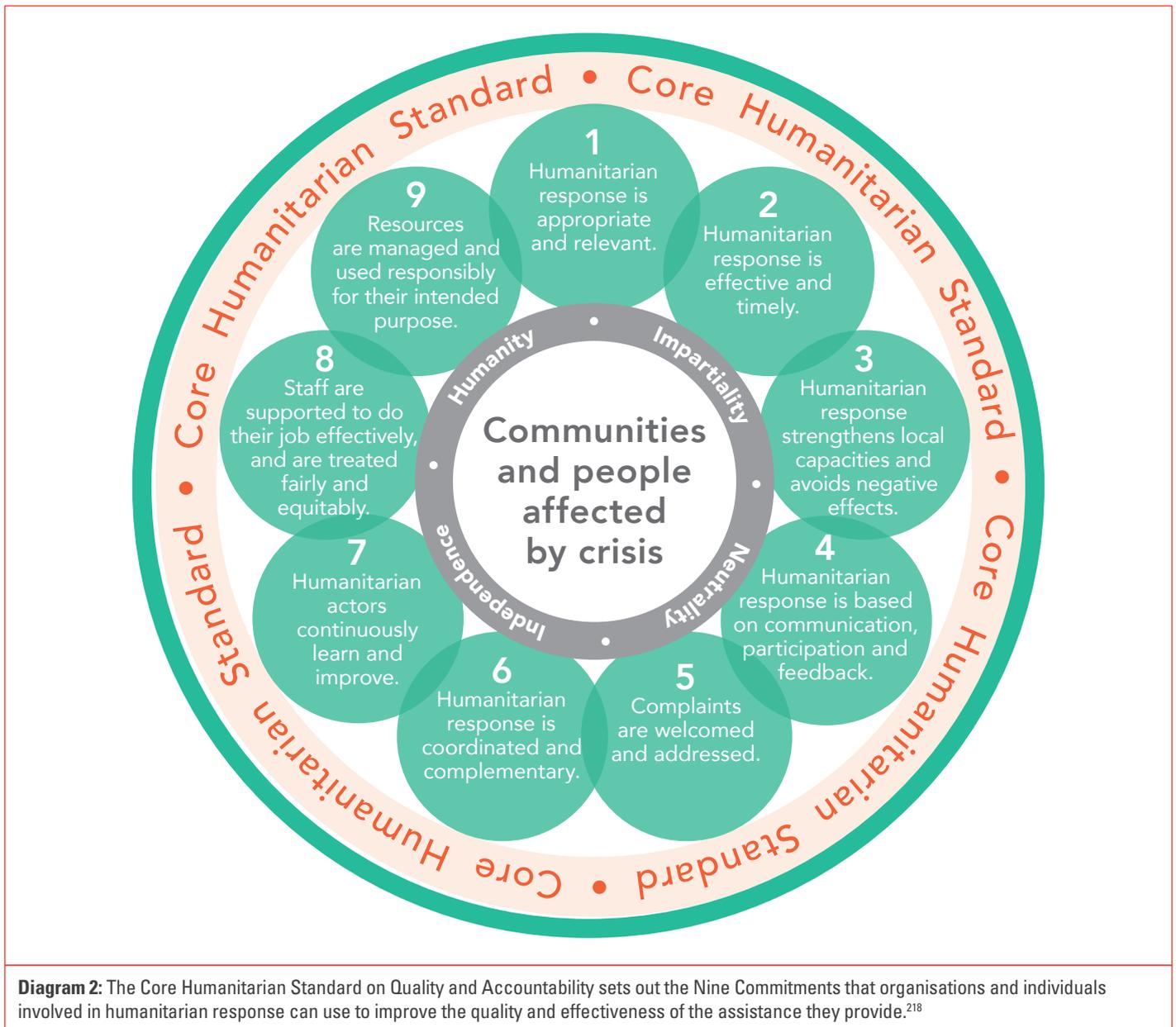
The CHS also advises that humanitarian organisations should have policies that set out commitments which take into account the diversity of communities, including disadvantaged or marginalised people, and to collect disaggregated data. (1.5). They must communicate in languages, formats and media that are easily understood, respectful and culturally appropriate for different members of the community, especially vulnerable and marginalised groups (4.2).

## 3.2 The Sendai Framework

The Sendai Framework for Disaster Risk Reduction 2015–2030 was the first internationally endorsed framework that consistently includes persons with disabilities in line with the Convention on the Rights of Persons with Disabilities. The framework is reflected in some of the Sustainable Development Goals adopted by the UN General Assembly in 2016. The Sendai Framework was adopted by UN member states on 18 March 2015 at the Third UN World Conference on Disaster Risk Reduction. It is a 15-year voluntary, non-binding agreement which recognises that the state has the primary role to reduce disaster risk, but that responsibility should be shared with other stakeholders including local government, the private sector and other actors. At an international level the framework aims to enhance cooperation between health authorities and other relevant stakeholders to strengthen country capacity for disaster risk management for health.<sup>216</sup>

The Sendai Framework aims for the substantial reduction of disaster risk and losses in lives, livelihoods and health. It also aims to reduce losses in the economic, physical, social, cultural and environmental assets of persons, businesses, communities and countries. It places a strong emphasis on disaster risk management (as opposed to disaster management) and health resilience is strongly promoted throughout. It advocates for a more people-centred preventative approach to disaster risk. Governments are directed to engage with relevant local stakeholders, including women, persons with disabilities, poor people, the community of practitioners, and older persons in the design and implementation of policies, plans and standards (Preamble: 7).<sup>217</sup>

Several of the Sendai guiding principles outline an approach that should be engaged in order to support those affected by dementia. This includes more inclusive engagement and better data collection. It emphasises the need for empowerment and inclusive, accessible and non-discriminatory participation, and asserts that a gender, age, disability and cultural perspective should be integrated in all policies and practices. It calls for the strengthening of design and implementation of inclusive policies and social safety-net mechanisms, and the need to empower and assist people disproportionately affected by disasters.



### 3.3 Charter on Inclusion of Persons with Disabilities in Humanitarian Action

In 2016, the UN Secretary-General report for the World Humanitarian Summit recognised that persons with disabilities are among the most marginalised in any crisis-affected community.<sup>219</sup> In recognition, a Charter on Inclusion of Persons with Disabilities in Humanitarian Action was launched during the Summit and includes a commitment to develop globally-endorsed UN system-wide guidelines on the inclusion of persons with disabilities in humanitarian action.<sup>220</sup> The guidelines are currently in development, in an initiative led by the Inter-Agency Standing Committee (IASC) and are expected in 2019.

The non-legally binding Charter was developed with over 70 stakeholders from states, UN agencies, the international civil society community, and global, regional and national organisations of persons with disabilities (see [www.humanitarianism.org](http://www.humanitarianism.org) for latest list of endorsing stakeholders). The Charter contains fourteen commitments

under the headings: non-discrimination; participation; inclusive policy; inclusive response and services; and cooperation and coordination. By endorsing the Charter, stakeholders commit to ensuring humanitarian action is inclusive of persons with disabilities. They ensure this by lifting barriers persons with disabilities are facing in accessing relief, protection and recovery support, and by ensuring their participation in the development, planning and implementation of humanitarian programmes.<sup>221</sup>

This Charter is open for endorsement by states and governments, UN agencies, organisations involved in humanitarian contexts, and organisations of persons with disabilities.<sup>222</sup> Under the Charter, persons with disabilities include those who have long-term physical, psychosocial, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in, and access to, humanitarian programmes.

### 3.4 2030 Agenda for Sustainable Development

On 1 January 2016, the 17 Sustainable Development Goals (SDGs) of the 2030 Agenda for Sustainable Development officially came into force.<sup>223</sup> A consortium of disability organisations published a position paper on the SDGs recognising the 2030 Agenda for Sustainable Development includes persons with disabilities (as opposed to previous development goals). It also recognised that persons with disabilities strongly believe that only by utilising the UN Convention on the Rights of Persons with Disabilities (CRPD) as a guiding framework in implementing the SDGs, will it be ensured that exclusion and inequality are not created or perpetuated.<sup>224</sup>

The SDGs call for all countries to mobilise efforts to end all forms of poverty, fight inequalities and tackle climate change, while ensuring that no-one is left behind. The SDGs recognise that ending poverty must go hand-in-hand with building economic growth and addressing social needs health, social protection, and job opportunities. While the SDGs are not legally binding, governments are expected to establish national frameworks for their achievement. Furthermore, the SDGs are primarily seen as mechanisms for developmental policies and programmes, rather than humanitarian relief. Having said that, the SDGs cannot truly 'leave no-one behind' if they do not apply to marginalised groups in emergencies settings.

Goal 3 addresses the need for 'Ensuring healthy lives and promoting the well-being at all ages'. More specifically target 3.4 aims by 2030, to 'reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being'. However, dementia is not currently included as an indicator for this target, with only four NCDs (cardiovascular disease, cancer, diabetes or chronic respiratory disease) currently tracked. Whilst the indicator is lacking, this target does provide a further mandate to protect the lives of people living with dementia (as an NCD) who are at risk of premature mortality if they do not receive support in humanitarian crises. SDG target 3.8. aims to 'achieve universal health coverage (UHC), including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all'. The continuum of UHC services includes promotion, prevention, treatment, rehabilitation, and palliative care, most of which is necessary for adequate dementia care.

Goal 10 focuses on reducing inequalities, with target 10.3 seeking to 'Ensure equal opportunity and reduce inequalities of outcome, including by eliminating discriminatory laws, policies and practices and promoting appropriate legislation, policies and action in this regard'. The indicator for 10.3 measures the 'proportion of the population reporting having personally felt discriminated against or harassed within the previous 12 months on the basis of a ground of discrimination prohibited under international human rights law'. The UN CRPD requires states to ensure that persons with disabilities are protected in

situations of risk or humanitarian emergency (Article 11) and therefore lack of adherence to Article 11 of the CRPD could be monitored under SDG 10.3.

Goal 11 on sustainable communities aims to 'significantly reduce the number of deaths and the number of people affected ... caused by disasters, including water-related disasters, with a focus on protecting the poor and people in vulnerable situations' (11.5). People living with dementia, as an at-risk group, should therefore be offered protection under this target. Target 11.b under Goal 11 also calls for 'resilience to disasters, and develop and implement, in line with the Sendai Framework for Disaster Risk Reduction 2015-2030, holistic disaster risk management at all levels'.

### 3.5 Madrid International Plan of Action on Ageing

The Madrid International Plan of Action on Ageing (MIPAA) and the Political Declaration was adopted at the Second World Assembly on Ageing in April 2002.<sup>225</sup> It was the first international agreement which recognises older people as contributors to their societies, and identifies the specific actions needed to ensure equal access of older persons to services during and after humanitarian emergencies. Furthermore, MIPAA calls upon member states to enhance the positive contributions of older persons in reconstruction and reconstruction efforts, and to identify good practices and challenges encountered.<sup>226</sup>

MIPAA also calls upon member states to 'provide programmes to help persons with Alzheimer's disease and mental illness due to other sources of dementia to be able to live at home for as long as possible and to respond to their health needs'.<sup>227</sup>

A challenge to MIPAA's implementation and monitoring, in both development and humanitarian contexts, has been a lack of age-disaggregated data in many countries.<sup>228</sup> Gaps between policy and practice, and the mobilisation of sufficient human and financial resources have also been noted as major constraints.<sup>229</sup>

The Report of the Secretary-General prepared for the third review and appraisal of the MIPAA in 2017 reflected on the inclusion of older persons in humanitarian response, taking a regional analysis. All regions were demonstrably lacking, with just a small number of countries recognised as having introduced some age-sensitive provision (including Anguilla, Austria, Barbados, Bulgaria, the Cayman Islands, Colombia, Croatia, Dominican Republic, Latvia, Sudan, Trinidad and Tobago, UK, and approximately half of the countries in Asia and the Pacific (ESCAP) region).<sup>230</sup> The ESCAP regional review reported that some countries in the region reported efforts to include older persons in disaster, but their efforts were not systematic and remained generic. The ESCAP report called for more efforts to harness older persons' potential in disaster preparedness, and to systematically include them in all phases of humanitarian and disaster relief programmes.<sup>231</sup>

### 3.6 IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action

The World Humanitarian Summit made a commitment for the development of globally-endorsed UN system-wide guidelines on the inclusion of persons with disabilities in humanitarian action. In July 2016, the Inter-Agency Standing Committee (IASC) endorsed the establishment of a time-bound task team to develop the guidelines. The task team is led by a tripartite co-chairing agreement comprising UNICEF, the International Disability Alliance, and Humanity and Inclusion. The task team is composed of: DPOs; NGOs; UN agencies; ICRC; IOM; governments; ECHO; IASC Secretariat; and the IASC Mental Health Psychosocial Support Reference Group.<sup>232</sup>

A thorough process was agreed among the task team members based on humanitarian stakeholders' experiences of including persons with disabilities in humanitarian action. It was also based on the perspectives of organisations of persons with disabilities and the challenges they face before, during and after a crisis to participate in and access humanitarian assistance and protection.

The aim of the guidelines is to assist national, regional and international humanitarian actors to better understand, respect, promote and fulfil the rights of persons with disabilities in humanitarian settings. They will be drafted to comply with, and complement, existing standards and guidelines. This is to ensure issues related to disability become visible and actionable (within for example, the Core Humanitarian Standards, Sphere, Humanitarian inclusion standards for older people and persons with disabilities and others). The guidelines will be published in 2019 and if they adequately address all disabilities could fill the gap in humanitarian support guidance for people with cognitive and psychosocial disabilities.

### 3.7 IASC 2007 Guidelines on Mental Health & Psychosocial Support in Emergencies Settings

In 2007, the Inter-Agency Standing Committee (IASC) issued guidelines to enable humanitarian actors to plan, establish and coordinate a set of minimum multi-sectoral responses to protect and improve people's mental health and psychosocial wellbeing during an emergency. The guidelines offer advice on how to facilitate an integrated approach to address the most urgent mental health and psychosocial issues in emergency situations. The core premise behind the guidelines is that, in the early phase of an emergency, social supports are essential to protect and support mental health and psychosocial wellbeing. In addition, the guidelines recommend selected psychological and psychiatric interventions for specific conditions.

While the focus is on acquired mental health and psychosocial conditions and wellbeing in humanitarian settings, the guidelines also include 'pre-existing problems (e.g. severe mental disorder)' which should be interpreted as including dementia under the guidelines definitions. The guidelines also highlight the vulnerability of people with 'severe physical, neurological or mental disabilities or disorders' in community

and institutional settings. Action Sheet 6.3 offers actions to protect and care for people with 'severe mental disorders and other mental and neurological disabilities living in institutions' during emergencies. This action sheet focuses mostly on the emergency-related needs of people with mental conditions living in psychiatric institutions. However, it advises the actions also apply 'to people with other chronic and severe mental and neurological disabilities', which would therefore include dementia.<sup>233</sup> In brief the four actions are:

1. Ensure that at least one agency involved in healthcare accepts responsibility for ongoing care and protection of people in institutions.
2. Mobilise human resources from the community and the health system to care for people who have been abandoned.
3. Protect the lives and dignity of people living in psychiatric institutions.
4. Enable basic health and mental healthcare throughout the emergency.

### 3.8 2010 Health Information System on refugees

In 2010 the Office of the United Nations High Commissioner for Refugees (UNHCR) and partners developed a standardised health information system to monitor camp-based refugee health programmes.<sup>234</sup> The Health Information System Reference Manual (HIS) was published in 2010. The HIS provided clear guides to train staff at the camp level on how to standardise data collection and reporting in order to increase availability and accessibility of refugee health data to decision-makers. Objectives were to: rapidly detect and respond to health problems; monitor trends and address healthcare priorities; evaluate effectiveness; and ensure resources are correctly targeted to the areas and groups of greatest need. The Reference Manual has an emphasis on communicable diseases, nutrition and maternal health. The case definitions that accompany the 2010 HIS include a category of 'chronic disease' which dementia would be categorised as. The case definitions also include a category of 'mental health or substance use problem or epilepsy' however whilst dementia should fall within this category, there is no explicit reference in the main body of the case definitions or within the annex detailing mental health conditions. This could mean that no-one using the HIS has been considering people living with dementia in such situations.

A useful element of the HIS is its priority goal to produce reliable information on death rates in refugee populations. The HIS recommends that direct and underlying causes should be recorded for every death. This system should in theory result in more accurate data about the number of those who die as a result of dementia, although would require those recording the causes to have an adequate understanding of dementia, which is currently lacking. The manual's template tally sheets and morbidity reporting forms include general categories of 'chronic disease' and 'mental illness' which, depending on interpretation, could encompass dementia. Yet despite dementia being the seventh leading cause of death worldwide, this statistic has not

yet translated into technical advice for death classification in practice. It is therefore left out of the data collection templates included in the guidance, even as a co-morbidity. This is symptomatic of a wider issue surrounding the slow global recognition of dementia as a public health priority until recent years.

### 3.9 Integrated Refugee Health Information System

In 2018 UNHCR and partners began a roll out of a new health information system called the 'Integrated Refugee Health Information System' (iRHIS) which is currently being implemented on a country-by-country basis.<sup>235</sup> The new iRHIS contains 9 category definitions for identifying mental, neurological and substance use (MNS) problems, now including a separate entry for dementia. The new categories were designed by humanitarian practitioners and mental health practitioners and are 'system compatible with the modules of the mhGAP programme without additional complexity.' The new iRHIS allows health workers in refugee settings to more accurately classify individuals with MNS problems.<sup>236</sup>

The mobile and web application-based system is designed to collect and report refugees' medical records with the ability to synchronise data collected offline on tablets by health staff. This allows for aggregation of data via a dashboard and generated reports. The iRHIS can not only be viewed by camp and country level supervisors but can also be checked for updates by health centre practitioners. This provides staff with live updates of the current status of the health facility in which they work and a comprehensive overview of public health and WASH indicators at refugee camp level.<sup>237</sup>

The inclusion of dementia as a standalone indicator was decided due to the increased relevance of the condition as a global health priority and its inclusion in mhGAP. During the development of the category there were diverging opinions about whether to merge 'dementia' with 'delirium' (a brief and self-limiting condition, as opposed to dementia, which is slow but progressive). However, by adding a specifier specialists are able to classify dementia or delirium separately.<sup>238</sup>

Wide and full use of the iRHIS will mean people living with dementia are systematically recorded in refugee settings for the first time which should improve outcomes.

### 3.10 The Sphere Handbook 2018

The Sphere Project, now known as Sphere, was created in 1997 by a group of humanitarian non-governmental organisations and the Red Cross and Red Crescent Movement. Its aim was to improve the quality of their humanitarian responses and to be accountable for their actions. The Sphere Handbook was first piloted in 1998, with revised editions published in 2000, 2004, 2011 and 2018.

The 2018 Handbook<sup>239</sup> comprises the Humanitarian Charter, Protection Principles, the Core Humanitarian Standard and practical guidance for humanitarian actors on WASH, food security and nutrition and also shelter and settlement.

Dementia as a specific condition receives just one reference in the Handbook, within a listing of conditions on a sample routine health management information system surveillance reporting form provided in the appendix. The Handbook identifies additional support needs often required by older people and persons with disabilities including psychosocial disabilities. These umbrella groups in this context encompass people living with dementia. However specific reference to cognitive disabilities would offer better provision for people with dementia.

The Handbook recognises that barriers may restrict access by some groups and individuals, resulting in inequitable assistance. It highlights that barriers may lead to discrimination against women and children, older people, persons with disabilities or minorities. It also recommends providing information, in accessible formats and languages, about entitlements and feedback mechanisms, promoting outreach with 'hidden' at-risk groups, such as persons with disabilities.

### 2008 WHO Hutton Report

#### *Older people in emergencies: Considerations for action and policy development*

The 2008 WHO Hutton report into older people in emergencies is one of the few international policy documents that give clear advice on older people living with dementia in humanitarian settings. Hutton calls for relevant actors to 'develop strategies to ensure that existing healthcare systems develop capacity (infrastructure and knowledge) to meet the increasing proportion of older people who will be impacted by disasters in the future, taking into account medical, disability and mental health needs including dementia and Alzheimer's disease'.<sup>240</sup> The report also recognises that 'because women live longer than men they experience a greater proportion of their life with poor health and disability', and that older 'women are subject to some disabilities and diseases more than men' and are more likely to experience dementia.<sup>241</sup>

### 3.11 ADCAP Humanitarian Inclusion Standards for Older People and People with Disabilities

The Humanitarian Inclusion Standards for Older People and People with Disabilities<sup>242</sup> were launched in March 2018, updating the 2015 pilot Minimum Standards for Age and Disability Inclusion in Humanitarian Action. The Standards, developed by the Age and Disability Capacity Building Programme (ADCAP), are designed to ensure older people and people with disabilities are included during emergency responses, both accessing assistance and supporting participation in the decision-making processes that affect them.

The Standards give practitioners and organisations clear actions to protect, support and engage older people and people with disabilities in their work. They provide guidance to identify and overcome barriers to participation and access in diverse contexts, and at all stages of the humanitarian programme.

For older people living with dementia, or for those whose dementia causes disability, implementation of these Standards in emergency settings would ensure that they are identified, enjoy safe and equitable access to assistance, become more resilient post-emergency, and participate meaningfully in decisions that affect their lives.

### Humanitarian Inclusion Standards for Older People and People with Disabilities<sup>243</sup>

- 1 Identification:** Older people and people with disabilities are identified to ensure they access humanitarian assistance and protection that is participative, appropriate and relevant to their needs.
- 2 Safe and equitable access:** Older people and people with disabilities have safe and equitable access to humanitarian assistance.
- 3 Resilience:** Older people and people with disabilities are not negatively affected, are more prepared and resilient, and are less at risk as a result of humanitarian action.
- 4 Knowledge and participation:** Older people and people with disabilities know their rights and entitlements, and participate in decisions that affect their lives.
- 5 Feedback and complaints:** Older people and people with disabilities have access to safe and responsive feedback and complaints mechanisms.
- 6 Coordination:** Older people and people with disabilities access and participate in humanitarian assistance that is coordinated and complementary.
- 7 Learning:** Organisations collect and apply learning to deliver more inclusive assistance.
- 8 Human resources:** Staff and volunteers have the appropriate skills and attitudes to implement inclusive humanitarian action, and older people and people with disabilities have equal opportunities for employment and volunteering in humanitarian organisations.
- 9 Resources management:** Older people and people with disabilities can expect that humanitarian organisations are managing resources in a way that promotes inclusion.

While the Standards only refer specifically to dementia once, the recommendations throughout can apply to those affected by dementia. Dementia is included in the guidance by means of its definition of disability. It defines persons with disabilities as including those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. Throughout the

Standards, actions and guidance are recommended to include people with ‘intellectual and psychosocial disabilities’ and this term implicitly includes people living with dementia in this context.

The Standards advise that particular attention is paid to barriers that hinder free movement, use of facilities, and access to information by people with physical, visual, sensory, intellectual or psychosocial disabilities. Specific considerations of greater impact for people with ‘intellectual and psychosocial disabilities’ are highlighted, and associated actions recommended.

For example:

- the need to consider that a lack of staff training and stigma makes it more difficult for people with psychosocial disabilities to access health services (under 2.2);
- address and monitor barriers to accessing protection response services, ensuring for example that people with psychosocial disabilities have access to therapeutic support provided as part of the mental health and psychosocial support service, if they need this (under 2.4);
- that people with intellectual and psychosocial disabilities might be at greater risk and should be involved in the identification, assessment and monitoring of such risks (under 3.2);
- the need to promote the meaningful participation of older people and people with disabilities in decision-making, including inviting people with different types of disability such as intellectual or psychosocial disabilities (under 4.2); and
- ensuring that inter-agency coordination mechanisms are representative of, and accessible to, people with psychosocial or intellectual disabilities (under 6.1).

The Standards advocate for awareness-raising sessions with health staff and community members on the potential health risks and barriers faced by older people, and children and adults with disabilities that may be overlooked (such as the implications of higher prevalence of non-communicable diseases for older people and people with disabilities).<sup>244</sup> Dementia is one of the main non-communicable diseases, and disproportionately affects older people.

*“During humanitarian emergencies, agencies need to work quickly to identify people living with dementia and then to address their support needs. Ahead of a crisis, governments, agencies and civil society need to work together to plan for people living with dementia. Cross-sector collaboration is crucial.”*

**Amy Little – Executive Lead, Global Alzheimer’s & Dementia Action Alliance**

# Dementia focused frameworks and tools

International frameworks and standards are increasingly recognising the need for an inclusive approach, with more recently developed guidelines identifying previously overlooked groups such as older people and those with disabilities. Yet inclusive implementation of existing frameworks and tools remains a challenge and inaction on dementia cannot continue. Humanitarian actors voice a lack of understanding of dementia – both its scale and how to address the needs of those living with it. This section looks at some of the dementia-specific tools that can be used in conjunction with international frameworks.

## 4.1 Global Action Plan on the Public Health Response to Dementia

The WHO Global Action Plan on the Public Health Response to Dementia 2017-2025 (Global Plan)<sup>245</sup> aims to improve the lives of people living with dementia, their care supporters and families, while decreasing the impact of dementia on communities and countries. The Global Plan was unanimously adopted by WHO member states in May 2017 and provides a set of actions to realise the vision of a world in which dementia is prevented and people living with dementia receive the care and support they need to live a life with meaning and dignity.

The Global Plan recommends global targets and activity under seven areas for action: dementia as a public health priority, dementia awareness, risk reduction, diagnosis, care and treatment, support for care partners, information and data, and research. For times of humanitarian emergencies, action area 4 of the Global Plan (on diagnosis, treatment, care and support) recommends that ‘planning responses to and recovery from humanitarian emergencies must ensure that individual support for people with dementia and community psychosocial support are widely available’. The targets and recommended activity within the Global Plan provide crucial guidance for governments and local, national and international partners to advance health and care system strengthening to meet the needs of people affected by dementia.

The unmet needs of people living with dementia in times of stability are inevitably exacerbated by times of crisis. One of the most urgent targets is for 75 per cent of countries to have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025. Achievement of this target and the wider recommendations within the Global Plan will help to improve the resilience and preparedness of countries to support those living with dementia when humanitarian emergencies do occur. By increasing dementia awareness and creating health and care systems that meet the needs of people living with dementia, the ability for humanitarian actors to identify and support this at-risk population will be strengthened.

Case study:

### Dementia Friendly Initiatives

The dementia-friendly approach originated in Japan and was then championed by Alzheimer’s Society in England and Wales and other countries as a method of increasing dementia awareness. Now it has been adopted by countries around the world. It is capturing the imagination of communities, policy makers and researchers globally and is recognised in national dementia policies and the WHO Global Action Plan on Dementia. The dementia-friendly approach and wider dementia awareness programmes have the potential to support emergency preparedness efforts; however at the time of writing, only in Japan has this approach been taken.

Alzheimer’s Disease International has published guidance on the principles of dementia-friendly communities and publications on existing initiatives worldwide: <https://www.alz.co.uk/dementia-friendly-communities>

An example dementia awareness programme is the Dementia Friends model. This volunteer-led movement aims to tackle the stigma and discrimination people with dementia can face globally. The short (usually 45 minute) programme is delivered face-to-face by volunteers or online in some countries. There are more than 50 Dementia Friends type programmes around the world, led by Alzheimer associations and other organisations. Every Dementia Friends programme is different, tailored depending on the country, and sometimes named differently to suit the cultural context. Organisations coordinating Dementia Friends programmes work collaboratively under the Global Dementia Friends Network, hosted by Alzheimer’s Society. Not only is the initiative helping to increase levels of dementia awareness in communities worldwide, but there is also scope for tailored sessions to be developed for humanitarian actors.

Action area 2 of the Global Plan (Dementia awareness and friendliness) sets global targets on dementia awareness:

- Target 2.1: 100 per cent of countries will have at least one functioning public awareness campaign on dementia to foster a dementia-inclusive society by 2025.
- Target 2.2: 50 per cent of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025.

Dementia awareness will help to ensure humanitarian actors understand the need to screen for and manage dementia, and that communities are sensitised to respond. Preparedness can also help to ensure community members are able to recognise the symptoms of people living with dementia, reducing reliance on rescue workers.

#### 4.2 WHO Mental Health Gap Action Programme

Gaps in knowledge of primary care physicians in recognising and managing dementia have been identified by health professionals working in the humanitarian context as a barrier to people receiving a diagnosis and their specific care needs being addressed.

The WHO Mental Health Gap Action Programme (mhGAP) aims to scale up services for mental, neurological and substance use disorders for countries, especially those with low- and middle-incomes.<sup>246</sup> Under mhGAP, WHO has produced a range of tools to provide non-clinical diagnosis for conditions including dementia. The mhGAP Intervention Guide for mental, neurological and substance use disorders in non-specialised health settings (version 2.0)<sup>247</sup> and accompanying mhGAP Training Manual and support materials<sup>248</sup> are the most useful tool to date for dementia diagnosis and support in humanitarian settings. It provides practical guidance for diagnosis and management of dementia, including support for carers.

The guide and manual are intended for non-specialist healthcare providers where access to specialists and treatment options is limited and can be used to build capacity in the assessment and management of people living with dementia in low-resource settings. Yet via consultation with humanitarian actors during research for this report, the dementia chapters of the mhGAP resources are currently not being prioritised in humanitarian settings.

Further, the 2015 mhGAP Humanitarian Intervention Guide (mhGAP-HIG), a shorter guide which extracts what was seen as the absolute minimum in extremely resource-poor settings, does not include the content on dementia from the wider mhGAP suite of resources or a reference to the condition. While much of the guidance in the shorter mhGAP-HIG document could relate to those living with dementia, its use is therefore limited as a tool for ensuring inclusion of people living with and affected by dementia in humanitarian settings, despite such inclusion in parent documents.<sup>249</sup> We would recommend an explicit reference to dementia in any future versions of the mhGAP-HIG in order to ensure protection, social support, access to essential services and prevent human rights abuses for people living with dementia in humanitarian settings.

Despite the challenges of a humanitarian crisis, mhGAP guidelines and resources can be successfully implemented to train primary care physicians in low- and middle-income countries.<sup>250</sup> For example, in 2015 mhGAP-HIG training was delivered to build the capacity of mental health workers in refugee primary health care settings in seven sub-Saharan African countries. Most of the facility-based staff reported improved clinical skills as shown by the questionnaires they were asked to fill, with an average of 81 per cent of clinicians agreeing that their assessment, diagnostic and management skills had improved.<sup>251</sup>

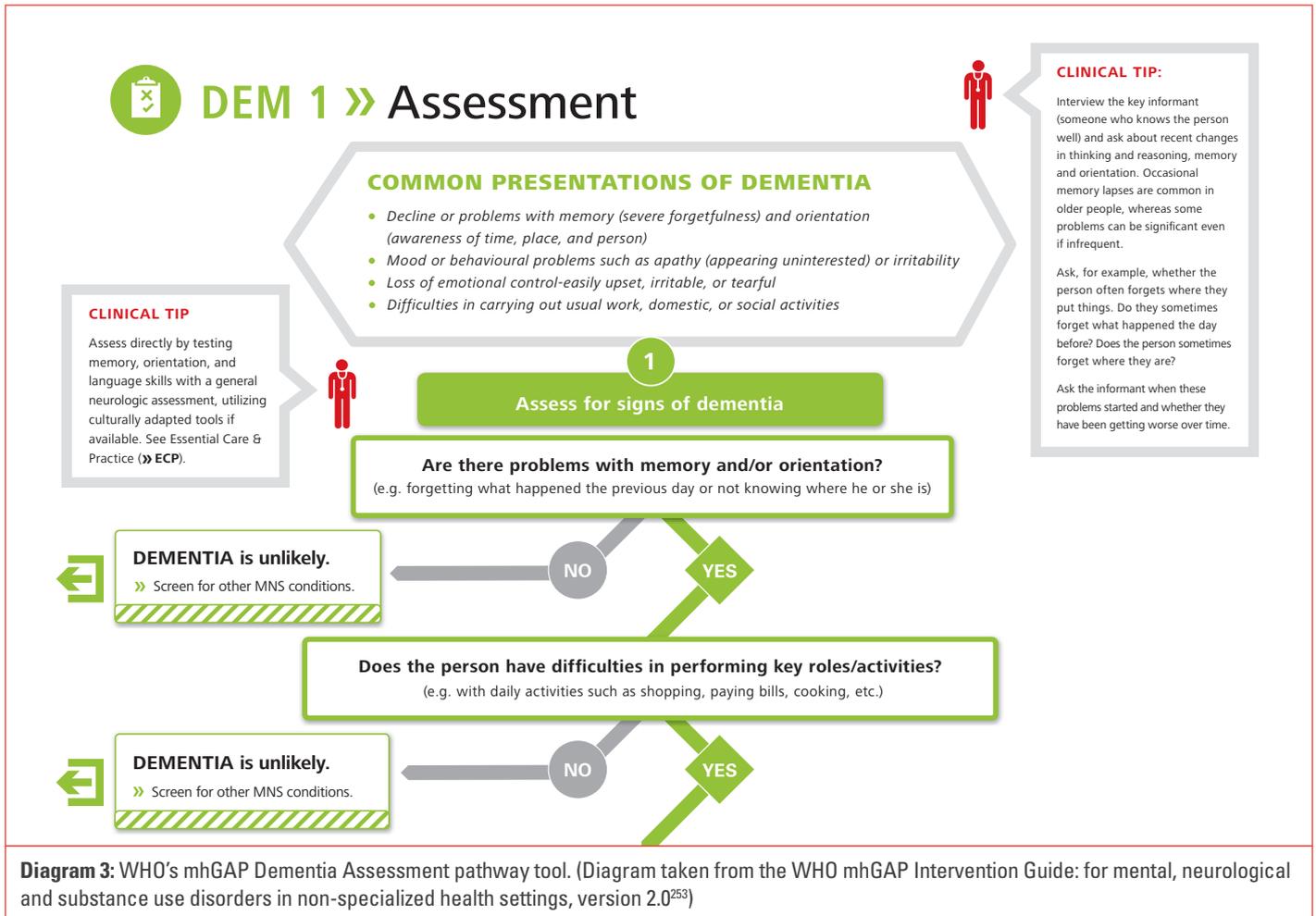
Resources included in the Intervention Guide and associated training materials include indicator questions (testing orientation, memory and language) that can be asked to the person displaying symptoms of dementia, as well as someone who knows them well. Some example questions are shown below. The interviewer then uses the Dementia Assessment pathway (see diagram 3) as a tool to assess cognitive decline for signs of dementia. The Training Manual Supporting Material provides practical guidance on the management of dementia.<sup>252</sup> Wider dissemination of the mhGAP suite of tools is needed, including resource and support to ensure uptake and systematic use by humanitarian actors.

#### Testing orientation, memory and language

##### Example of questions:

1. Tell them three words (e.g. boat, house, fish) and ask them to repeat after you.
2. Point to their elbow and ask, "What do we call this?"
3. Ask below questions:
  - What do you do with a hammer? (*Acceptable answer: "Drive a nail into something"*).
  - Where is the local market/local store?
  - What day of the week is it?
  - What is the season?
  - Please point first to the window and then to the door.
4. Ask, "Do you remember the three words I told you a few minutes ago?"

WHO's mhGAP indicator questions to test orientation, memory and language © World Health Organization



### 4.3 Global Dementia Observatory

The Global Dementia Observatory (GDO) is a data and knowledge exchange platform that offers easy access to vital dementia data across policies, service delivery, information and research. The GDO supports countries in measuring progress on dementia actions outlined in the Global Dementia Action Plan and assists them in strengthening policies, service planning and health and social care systems for dementia. The GDO will also monitor progress on the implementation of the Global Action Plan on Dementia. The recent launch of the GDO means that it has not yet compiled large data sets. However, initial reports offer interesting insights into national dementia training and education of non-health professionals who could be involved in emergency settings.

*“In extreme resource-poor and desperate situations where we often work, it will be difficult to add dedicated dementia programmes, but we can do much more to promote the dignity and safety of people living with dementia.”*

**Peter Ventevogel – Senior Mental Health Officer,  
United Nations High Commissioner for Refugees (UNHCR)**

### 4.4 Local dementia-focused tools

Dementia-focused organisations, including Alzheimer’s Disease International, Dementia Alliance International and national Alzheimer associations, have developed a significant body of tools, guidance and resources, many of which may be useful or could be adapted for the humanitarian context. A list of national Alzheimer associations can be found via the Alzheimer’s Disease International website <https://www.alz.co.uk/associations>.

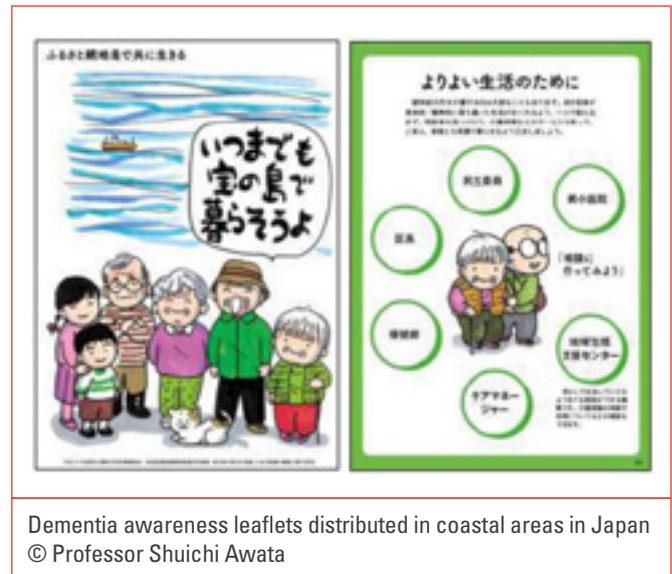
It is important for humanitarian actors to recognise the expertise and resources from local and national actors when addressing the specific needs of people living with dementia. By actively reaching out to dementia-focused organisations and dementia health and care experts, humanitarian actors can use existing local expertise and resources, such as translated materials using language relevant to the affected population. This will ensure local and national actors lead a more coordinated and collaborative emergency response for people living with dementia.

Case study:

### Learning from a crisis – Japan’s preparedness approach

The Great East Japan Earthquake, with a magnitude of 9.0 on the Richter scale, occurred on March 11, 2011. One of the after effects was a tsunami that damaged nuclear power plants in Fukushima Prefecture, followed by the release of radioactive material. As a result 19,418 people were killed, 65 per cent of whom were over the age of 60.

In response to the large numbers of older people affected, innovative ways were developed to learn from the impact of the natural disaster on people living with dementia and various approaches were trialled. A community based interdisciplinary team was established on Aji Island, meeting regularly to identify how to support the lives of people living with dementia. A support framework was established to provide initial-phase intensive support in the aftermath of the disaster. Initiatives that developed over time included: pamphlet distribution in coastal areas to increase dementia awareness; the development of wide-ranging dementia-friendly community initiatives; and improved services including diagnosis and post-diagnostic support. Pre-diagnosis support involved assessment and information sharing to facilitate diagnosis when needed. Post-diagnostic information and emotional support were introduced, as well as coordination of integrated care.<sup>254</sup>



Dementia awareness leaflets distributed in coastal areas in Japan © Professor Shuichi Awata

Reflecting on the initiatives, Professor Shuichi Awata of the Tokyo Metropolitan Institute of Gerontology states that in Japan they *“are learning what a dementia-friendly community is through the experiences of disasters”*.<sup>255</sup> It is clear from this example that Japan is further ahead than many countries in its dementia policy and programming, and has applied its learning not just to support disaster preparedness, but also to the benefit of the everyday lives of people living with dementia.

# Recommendations and areas for action

It is clear that people living with dementia are largely overlooked in humanitarian response, despite their human right to assistance. This is representative of a wider issue of a lack of support for older people with disabilities and is compounded by a lack of global awareness of dementia and the associated stigma, despite being one of the leading

causes of death worldwide. People with dementia are clearly persons with specific needs and should therefore be recognised by humanitarian actors. We propose the following recommendations so that no-one is left behind in humanitarian response simply because of their medical condition, age or their disability.

## 5.1 Recommendations

- 1 Ensure accessibility** by eliminating the physical, communication, social/attitudinal and institutional barriers to the inclusion of those with dementia in humanitarian action.
- 2 Develop and universally use fully inclusive frameworks, standards and tools** to ensure support for people with dementia in humanitarian emergency response.
- 3 Create dementia awareness** initiatives to aid disaster preparedness, humanitarian workforce understanding and community resilience in humanitarian emergencies.
- 4 Collect, analyse, report and utilise disability disaggregated data** which includes cognitive disability, and ensure the data is accessible to all humanitarian actors.
- 5 Widen the evidence base** on the impact of dementia in humanitarian settings and solutions to support people living with the condition.
- 6 Foster collaboration between humanitarian agencies and dementia specialists** via local, national and global NGOs/DPOs and people living with dementia, to provide specialist input across the humanitarian programme cycle, from preparedness plans to evaluation.
- 7 Monitor inclusion of people living with dementia** as part of improved inclusive action for those with cognitive and psychosocial disabilities in humanitarian programming.
- 8 Invest in inclusive humanitarian action** ensuring data collection and monitoring for cognitive and psychosocial disabilities is included within funding requirements to ensure those living with dementia are not left behind.
- 9 Dementia-focused NGOs** and disabled peoples organisations develop processes for emergency preparedness and response and advise humanitarian actors on dementia-specific needs and best practice.

## 5.2 Areas for action

Ensuring the protection and support of people with dementia in humanitarian emergencies is a collective responsibility. Collaboration is urgently needed between humanitarian agencies, governments, inter-governmental organisations,

donors, local, national and global NGOs/DPOs and people living with dementia. Below we outline practical areas for action for various actors.

### Humanitarian actors (programmers, cluster leads, local actors, humanitarian leadership, and humanitarian workers) should:

#### Preparedness

- Ensure that all humanitarian response and preparedness plans are inclusive and ensure protection and access to dementia-specific assistance.
- Work with dementia-focused organisations to provide specialist input on programme design. Utilise the support of dementia and older people's NGOs (especially national Alzheimer associations) to help fill gaps in health and social care expertise. Explicitly refer to the specific protection needs of people with all types of disability, including those with cognitive or psychosocial disabilities in safeguarding and protection policies and training for humanitarian staff. Disseminate information and tools relevant to dementia for continual professional development.

### Needs assessment and analysis

- Use tools, guidelines and standards on inclusion to develop humanitarian programming/response (such as mhGAP, Washington Group Extended Set of Questions, integrated Refugee Health Information System (iRHIS), ADCAP Minimum Standards for Age and Disability Inclusion in Humanitarian Action, IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action).
- Consult and collaborate with people affected by dementia and DPOs in the development of needs assessments.
- Train community outreach volunteers and staff to identify and support people with dementia, which may include persons locked in homes or hidden away and not presenting themselves to humanitarian workers, especially in communities with severe dementia stigma and social-cultural discrimination.
- Carefully assess the nutritional needs of persons showing signs of dementia, in relation to, for example, micronutritional needs, quality of proteins and the content of other nutrients, as well as processed food.
- Carefully assess assisted eating needs and preparation support needed (e.g. liquid form) in line with nutritional needs.
- Understand the basic principles of palliative care provision and how to access available services in order to assess and deliver palliative care needs.
- Assess the need for psychological first aid and scalable psychological interventions to support people living with dementia.

### Strategic planning

- Work with specialist DPOs (such as national Alzheimer associations) to develop processes to identify those most at risk of being left behind during disaster recovery, such as those living with dementia.
- Include nutrient-rich foods in aid rations (general food rations with micronutrient requirements taken into account for those with additional needs).
- Anticipate provision of dementia-specific healthcare and support, including the provision of information, medicines and assistive devices.
- Ensure participation of DPOs and specialist organisations in cluster meetings to ensure inclusion of expertise on varied at risk groups including those with dementia.

### Resource mobilisation

- Work with dementia-focused organisations to seek specialist input during emergency response (for example within coordination committees, as workers or volunteers on the ground, or in an advisory capacity).
- Use digital applications to assist data collection, analysis and monitoring with on and offline capability.

### Implementation and monitoring

- Address some of the barriers for people living with dementia in travelling to and accessing assistance. Provide seating, shade, safe drinking water, safe spaces and toilets at distribution points.
- Create systems for care supporters of those living with dementia to collect food, water and other emergency supplies on their behalf.
- Consider and continually review the location of support services or temporary accommodation for people with dementia and other cognitive or psychosocial disabilities, to offer optimal protection.
- Continually review accessibility of humanitarian services, communication and information to ensure inclusion of people with dementia.
- Adapt the language used when talking about dementia, ensuring the use of inclusive language and culturally appropriate terms (understanding that some cultures do not even have a word for dementia). Monitor the inclusion of persons with disabilities (including those with dementia and other cognitive disabilities) in humanitarian programming.
- Maintain disability disaggregated data across programme cycle.

## Governments, policy makers, donors and inter-governmental organisations should:

### Preparedness

- Ensure robust, funded and inclusive national emergency planning which includes indicators to measure inclusion of persons with dementia and all disabilities.
- Create fully inclusive local, regional and national disaster prevention and preparedness strategies that include disability provision for the emergency assistance of people living with dementia and those that support them.

- Incorporate provision for non-communicable diseases, older people and cognitive and psychosocial disability support needs into existing emergency-related policies, funding streams and resources, to ensure people living with dementia are not left behind.
- Adopt dementia awareness programmes utilising best practice from other countries as part of emergency preparedness.
- Actively seek advice, collaborate and build the capacity of dementia, disability and older people’s NGOs (especially national Alzheimer associations) to help fill gaps in health and social care dementia expertise.

**Needs assessment and analysis**

- Promote the use of tools, guidelines and standards on inclusion to develop humanitarian programming/response.
- Ensure comprehensive data collection on disability including cognitive disabilities like dementia, is accessible to all humanitarian actors.

**Strategic planning**

- Maintain a register of DPOs and specialists to ensure relevant expertise can be accessed in times of humanitarian emergency.

**Resource mobilisation**

- Invest in inclusive humanitarian action ensuring data collection and monitoring for cognitive and psychosocial disability support is included within funding requirements to ensure those living with dementia are not left behind.

**Implementation and monitoring**

- Use lessons learned and inclusive best practice delivered during humanitarian response to inform community reconstruction and improve post-emergency health and care systems for people affected by dementia.
- Report against international obligations (such as the CRPD) and non-binding standards (such as the Sendai Framework, Charter on Inclusion of Persons with Disabilities in Humanitarian Action, 2030 Agenda for Sustainable Development) to demonstrate disability inclusive humanitarian action.

**Organisations of persons with disabilities (DPOs), national Alzheimer associations and international NGOs (including those focused on dementia, disability and older persons) should:**

**Preparedness**

- Provide technical expertise and training to humanitarian actors on how to support people living with dementia (within programme design, during emergency response and in monitoring).
- Advise local, regional, national and international policy makers and donors in their development of emergency-related policies and interpretation of international standards to ensure inclusion of people affected by dementia.
- Advocate and raise awareness on the rights of people living with dementia to inclusive humanitarian assistance and the issues and challenges faced in emergencies.

**Needs assessment and analysis**

- Help to identify people living with dementia during disaster recovery and within displaced populations.
- Help to assess the barriers to accessing support for people living with dementia and their care supporters in humanitarian settings.

**Strategic planning**

- Share examples of good practice in inclusive humanitarian action that supports and protects people living with dementia.
- Identify appropriate focal points to participate in cluster meetings to advise on the needs of people living with dementia and similar conditions.

**Resource mobilisation**

- Support advocacy for the mobilisation of funding during humanitarian emergencies, to ensure those with additional needs including people living with dementia are not overlooked.

**Implementation and monitoring**

- Continually advocate for, and help to review, the accessibility of humanitarian services, communication and information to ensure inclusion of people with dementia.

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