Forgotten in a Crisis

Addressing Dementia in Humanitarian Response

People with dementia are being ignored in times of humanitarian crisis. *Forgotten in a Crisis: Addressing Dementia in Humanitarian Response* draws on the experiences of people affected by dementia during emergencies. This briefing summarises some of the report's key findings of how aid agencies, governments and local organisations can protect and support people living with dementia – before, during and after an emergency.

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.

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. 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.[1]

One in every 70 people around the world is impacted by crisis and urgently needs humanitarian assistance and protection.[2] Brutal changes to home, community structure and environment occur during a humanitarian emergency which can place all persons with disabilities at risk,[3] especially those with dementia and with other cognitive disabilities.

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.[4] 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 inter-governmental organisations, humanitarian agencies, governments, local partners, disabled people's organisations (DPOs), non-governmental organisations (NGOs), and donors.

GADAA Global Alzheimer's and Dementia Action Alliance

Alzheimer's Disease International

Alzheimer's Pakistan

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 towards 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.[5]

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.[6]

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.'[7]

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.

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.

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

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 carers would go out to the streets looking for help."

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

Milagros Negrón © Cromance Foto

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's earthquake response. 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.

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

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.

> *"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**

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.

Read the full report at: www.alz.co.uk/humanitarian.

References

1 Alzheimer's Disease International (2019) 'Dementia statistics'; and WHO (2017) 'Mental Health'

2 UNHCR (2018) Global humanitarian overview 2019, p.4

3 Handicap International (2015) Disability in humanitarian contexts: Views from affected people and field organisations, p.7

4 United Nations High Commissioner for Refugees (2019) 'Identifying persons with specific needs', Emergency Handbook, Version: 2.3

5 See: Humanitarian Inclusion Standards for Older People and People with Disabilities, Age and Disability Capacity Building Programme (ADCAP)

6 WHO and UNHCR (2015) mhGAP Humanitarian Intervention Guide (mhGAP-HIG): Clinical management of mental, neurological and substance use conditions in humanitarian emergencies

7 WHO (2017) Global action plan on the public health response to dementia 2017-2025

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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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