



OPEN LETTER

REVISED Giving voice to those directly affected by the COVID-19 pandemic – the experience and reflections of a person with dementia [version 2; peer review: 3 approved]

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Abstract

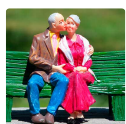
The coronavirus disease 2019 (COVID-19) pandemic presents unprecedented challenges to society. Behind the daily tally of deaths and cases of infection are individuals and families who are experiencing the ultimate consequence of this disease. Every aspect of our lives has been affected and these affects are amplified for those who have to cocoon and have conditions such as dementia. There is little opportunity to directly hear the experience of those ‘vulnerable adults’ who have been self-isolating for many weeks now. This letter takes the form of a reflective conversation with a person living with dementia. Honouring the principles of public and patient involvement (PPI), it is an attempt to give voice to the experience of one of the many thousands of vulnerable people during the COVID-19 pandemic. As well as describing the effect on her daily life, Helen describes what supports would help at this time. While the focus of attention at the moment is rightly on dealing with the effects of the virus in nursing homes, the many thousands of people living with dementia in the community should not be forgotten.

Keywords

Dementia, Covid19, PPI, experience



This article is included in the [Coronavirus \(COVID-19\)](#) collection.



This article is included in the [Ageing Populations](#) collection.

Open Peer Review

Reviewer Status

	Invited Reviewers		
	1	2	3
version 2 (revision) 05 Nov 2020			
version 1 28 May 2020	 report	 report	 report

1. **Steven R. Sabat** , Georgetown University, Washington, USA
2. **Damian Murphy** , Innovations in Dementia CIC, York, UK
3. **Éidín Ní Shé** , University College Dublin, Dublin, Ireland

Any reports and responses or comments on the article can be found at the end of the article.



This article is included in the [Public and Patient Involvement](#) collection.

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Author roles: **Rochford-Brennan H:** Conceptualization, Writing – Review & Editing; **Keogh F:** Conceptualization, Writing – Original Draft Preparation, Writing – Review & Editing

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REVISED Amendments from Version 1

Open letter V2 includes responses to suggestions from the reviewers. Additions have been made to recognize that Helen draws on the experience of others as well as her own experiences in this account. We have also referenced the fact that most people with dementia in Ireland live in the community. A summary of the suggestions and recommendations is provided at the end of the letter, which includes a suggestion from one reviewer to make more explicit the importance of peer support. This revised version also includes an update on the support Helen has been receiving. The letter was written in April and May, which was an early stage for the pandemic, and service responses for Helen have subsequently increased, largely through the use of technology.

Any further responses from the reviewers can be found at the end of the article

Disclaimer

The views expressed in this article are those of the author(s). Publication in HRB Open Research does not imply endorsement by the Health Research Board of Ireland.

This idea for this letter was inspired by an initial conversation with Helen Rochford Brennan (HR-B) who has been cocooning for over seven weeks at time of writing. She and her husband both fit the criteria of ‘extremely medically vulnerable’ as both are over 70 and each has a medical condition; dementia and a heart condition respectively (HPSC, 2020). Over the last five weeks Fiona Keogh (FK) from the Centre for Economic and Social Research on Dementia at NUI Galway had a series of follow-up conversations with HR-B about her experience of the coronavirus disease 2019 (COVID-19) emergency measures, how her life is affected and supports she has received from the health and social care system.

As the pandemic emerged, the emphasis was rightly on emergency measures, clinical care, hospital readiness and rapid responses. The voice of experts in epidemiology, infectious disease and public health necessarily dominated the information flows. These voices have provided welcome clarity and reassurance in difficult times. Their guidance has been widely respected and closely followed in Ireland and most other countries. As we move into the third month of COVID-19 in Ireland and the easing of some restrictions, we can begin the process of reflecting on the experience thus far, what has been learned and what our priorities might be in the coming months. This letter aims to provide a contemporaneous account of the experience of a person with dementia of living through this pandemic in order to inform these considerations. The practice of public and patient involvement (PPI) in research has become mainstreamed to the extent that many research funders require evidence of PPI in funding applications (for example, the Health Research Board). PPI recognises the unique value of the personal experience in understanding a medical condition and bringing that experience to bear in research and policy development (Ocloo & Matthews, 2016; Sabat, 2003). The right to be heard and to be involved in research and policy is

particularly important for people who are marginalised or whose condition makes it less likely that their voice will be heard (Cahill, 2019; Swaffer, 2018). Dementia is one such condition. People with dementia are mostly older; placing them at high risk of COVID-19. As dementia progresses it can affect a person’s ability to communicate or to comprehend complex information, such as that provided during a pandemic. They may be judged as having ‘no capacity’, thereby taking away their right to make almost any decision. If PPI was important before the pandemic, it is even more important now, to ensure that the voice of vulnerable people is heard at all stages of dealing with the current crisis. Those who will be directly impacted must have a role in shaping what health and social care services will look like now and into the future, and this is particularly true for people with dementia.

Helen lives at home with her husband in the outskirts of a small town in the west of Ireland. Their son lives and works in London. She was diagnosed with early onset Alzheimer’s disease in 2012 at the age of 62. Up to the time of diagnosis, Helen had a busy working life. Some time after her diagnosis, she became an active campaigner for rights and social justice in dementia. Her advocacy has led to her becoming involved in research on dementia which provided her with “a great outlet as well as an opportunity to meet and get support from peers”. She became an active member of the Irish Dementia Working Group (IDWG) which led to her involvement with Alzheimer Europe and the European Working Group of People with Dementia (EWG-PWD). She was elected Chairperson of this group in 2016 and serves on the Board of Alzheimer Europe in this capacity. Helen acknowledges that she may not seem like a ‘typical’ person with dementia but she reminds me that everyone has a life before dementia and that many aspects of her life are similar to many others; “every person’s circumstances are different and we each experience dementia in different ways so what is typical anyway?” While this letter describes Helen’s own experience, through her advocacy work and contact with peers, she is also drawing on the experience of others in her account.

Asked to describe the effect of cocooning on her life, Helen describes heightened anxiety, stress and isolation. The anxiety is ever-present – the ‘what if’ scenarios that play out in her head continuously. As well as having dementia, Helen is the carer for her husband and is finding this responsibility particularly stressful at this time. Normally if she felt anxious or stressed Helen would go for a walk or meet friends for a chat. These outlets are not available now. This sense of being cut-off and isolated, adds to the anxiety and stress. In this time period, Helen became physically unwell herself, emphasising the dynamic nature of everyday life and the need to keep modifying supports and responses as a person’s circumstances change. These challenges are similar to those of the many older people and people with medical conditions who are cocooning (Alzheimer Society of Ireland, 2020). However, dementia brings additional challenges. Forgetfulness creates obvious difficulties. People with dementia may need reminding to implement the basic guidance around social distancing. Small everyday occurrences for many of

us are magnified for Helen, such as misplacing a small medical device which cannot easily be replaced but is needed every day.

A critical challenge at this time is that people with dementia often don't seek out help because they may not realise they need it or they can forget what help is available, particularly if it is outside the usual range of supports (Werner *et al.*, 2014). For example, the Gardai and the postal employees are providing extra support at this time, but Helen forgot about this until a Garda called to her house to enquire if she needed anything. Another concern that is particularly relevant for people with dementia is 'use it or lose it' - the acceleration in loss of abilities and cognitive function in the absence of the stimulation posed by everyday living situations such as shopping, using transport, social situations and so on (Aguirre *et al.*, 2013; Mitchell, 2018). Helen articulates this concern strongly and describes her strategies to overcome it such as telephone conversations, attending virtual meetings and baking, which provides the discipline of following a recipe and remembering each step.

Helen and her husband receive 30 minutes of home support each week. Her husband receives support for his heart condition from a day hospital, with check-in phone calls and attendance at the day hospital if necessary. Helen also spent a short time in hospital and received follow-up care. Apart from these formal services, the only other formal support available to Helen is information and online resources. Helen called some helplines to assess what support might be available for people with dementia. These directed her to local services – none of which were operating at this time. Since this letter was first written in April/May 2020, additional support has come on stream for Helen. She now has zoom contacts with a dementia nurse specialist using her laptop. She also had a virtual consultation with a doctor from the dementia services team using the virtual assistant assistive technology device 'Alexa'. She is also receiving support for her role in caring for her husband. These contacts emphasise the usefulness and importance of technology in enabling new forms of service delivery.

Helen welcomes the *Community Call* initiative (Department of Rural and Community Development, 2020), and this approach of mobilising community support is very much in line with what she has advocated for many years. While she can access online information and seek support from *Community Call* fairly easily, Helen is conscious of the challenges for people with dementia. Firstly, the person must be able to identify and articulate their support needs, and secondly, they need to *proactively* seek out the relevant information, which is mostly online. The person also needs the necessary equipment (computer or smartphone), infrastructure (broadband connection) and skills to navigate online. Helen emphasises two practical supports which would really help people with dementia at this time. Firstly, human contact which is essential for reassurance and emotional support; and secondly, a simple information sheet specifically for people with dementia and their carers, sharing strategies and information they need at this time.

In spite of the fact that almost two thirds of people with dementia in Ireland live in the community, people with dementia can be 'invisible' in many respects (Pierse *et al.*, 2019). Many people with dementia are not diagnosed and are therefore are not in contact with any health service for their dementia. It is estimated that the majority of community-dwelling people with dementia in Ireland do not have a diagnosis (Cahill *et al.*, 2012). Many people who have a diagnosis use a wide range of generic (e.g. home support) and dementia-specific services (e.g. dementia adviser) with no centralised list. Practice-based registries could play a key role in identifying people with dementia who could be proactively contacted to establish their support needs and provide human contact and emotional support. The Chronic Disease Management Programme (HSE, 2019) creates in effect, a practice-based register of people with specific conditions which could be used to proactively provide telephone support and advice to patients at this time. However, dementia is not part of this programme.

Helen names the many positives in her life – she is not living alone, she can get outside in her garden and she has a supportive network of family and neighbours. She is adept at computers and social media with access to good broadband. She has a wide network of peers and colleagues she can contact by phone. She uses these resources to keep herself active and to keep the isolation and anxiety at bay. She describes herself as resilient but observes that "resilience can only stretch so far". Helen describes her own resilience as coming from her upbringing and her work and life experiences, but also from interventions that she has had the opportunity to access such as cognitive rehabilitation therapy (CRT). The latter is a psychosocial intervention which focuses on improving cognitive functioning in everyday life and supporting people to achieve the everyday goals that matter to them through developing and implementing strategies that work for them (Bahar-Fuchs *et al.*, 2013). There is some evidence that people with dementia and their carers who have experienced CRT sustain what they learned and continue to develop strategies for the challenges posed by dementia (Clare *et al.*, 2019).

Reflecting on Helen's experience, we identified the importance of an existing service infrastructure which can be adapted to respond in times of crisis. However, community-based services for people with dementia have historically been fragmented, underdeveloped and underfunded compared to other services (O'Shea *et al.*, 2017). There have been welcome developments in dementia services following on the publication of the National Dementia Strategy (Department of Health, 2014) such as the implementation of psychosocial interventions. However, this was from a base of close to zero, and so CRT and other psychosocial interventions are only available on a very limited scale in Ireland. The poor availability of many dementia-specific services and the variety of services people may access, makes it particularly difficult to proactively reach out directly to people with dementia to provide support, which is exactly the kind of action needed at this time. This situation is likely exacerbated now by the need to direct scarce resources into nursing homes where the spread of the COVID-19 virus is most acute (Department of Health, 2020). The years of

neglect of community-based supports for people with dementia are more obvious now than ever. Even in the middle of the current crisis, this seems an inescapable fact that must be addressed at the first opportunity.

While formal health services are important, people with dementia have long recognised the importance of a social model of support (Mental Health Foundation, 2015) and the development of dementia friendly or dementia inclusive communities has played an important role in building community responses, particularly in Ireland (Alzheimer Society of Ireland, 2016). Initiatives such as the *Community Call* are building on decades of rural and urban community development programmes in Ireland, as well as more recent initiatives such as Age Friendly Ireland and Dementia Inclusive Communities (Age Friendly Ireland, 2020; HSE, 2020). That is not enough, however, and there will be plenty of lessons to be learned from the current crisis, not least the need to have significant investment in home care services and supports (O'Shea, 2020a; O'Shea, 2020b). Keeping people out of nursing homes and building an eclectic continuum of care (O'Shea *et al.*, 2019) should be the legacy of this terrible virus, according to Helen. We suggest the following should feature in this continuum:

- The continuation of contact through phone calls and practical support for virtual contact through increased availability of assistive technologies;

- Continuation of the *Community Call* initiative (or similar) to mobilise community support;
- A simple information sheet as well as human contact;
- The inclusion of people with dementia on the chronic disease management programme registers;
- Support for increased use of peer to peer support, for example, through a post-diagnostic course or similar shared learning forum.

The National Dementia Office and the HSE have been making great strides to effect change in the dementia landscape in Ireland. But to do the job properly, they need resources to fund the changes that are necessary to keep more people with dementia living well in their own homes.

Consent

Written informed consent for publication of the participants' details was obtained from the participants.

Data availability

Underlying data

No data are associated with this article

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Open Peer Review

Current Peer Review Status:   

Version 1

Reviewer Report 03 June 2020

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 **Éidín Ní Shé** 

School of Nursing, Midwifery and Health Systems, C129, UCD Health Sciences Centre, University College Dublin, Dublin, Ireland

It was a privilege to read this letter. The authors, using an inclusive and participatory approach, weave the lived experience of Rochford-Brennan within the literature and current policy and practice.

The approach used in the writing of the letter is an exemplar of best practice in public and patient involvement I have come across.

We are provided valuable insight into the daily life of Rochford-Brennan. She notes that cocooning has increased experiences of anxiety, stress and isolation as she navigates the pandemic and being the primary carer for her husband. The cracks in community supports are laid out by the authors that need urgent resources and integrated approaches.

This letter should be read and reflected on by anyone interested in integrated patient-centred care in Ireland. Ideally, it should be at the top of the reading pile of our next government.

Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Yes

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

Is the Open Letter written in accessible language?

Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Health Systems, Public and Patient Involvement, Co-Design.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 12 Oct 2020

Fiona Keogh, National University of Ireland, Galway, Galway, Ireland

Many thanks Eidin for taking the time to review the letter and for your positive comments.

Competing Interests: No competing interests were disclosed.

Reviewer Report 02 June 2020

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Damian Murphy 

Innovations in Dementia CIC, York, UK

This excellent Open Letter builds to a call for better and more sustainable community based support across Ireland for people living with dementia. If anything I feel the call could be more powerful and explicit.

This open letter reports on a series of conversations between the authors, Helen and Fiona. The conversations cover Helen's experiences and reflections as a person living with dementia in the community during the COVID-19 crisis in Ireland. With the current emphasis rightly being on the situation in long term care, the letter is an important reminder that the majority of people with dementia still live in the community and that this crisis has revealed some particular areas to address.

The aim is for this contemporaneous account to help shape the priorities of health and social care services in the future. Helen's personal experiences and the reflections of both show how the COVID crisis has exacerbated issues of anxiety, isolation and the potential loss of confidence and

skills amongst people living with dementia. Their conversation also highlighted some long standing gaps in community support that are in need of urgent filling.

Rationale

I thought this was really clear. OK the focus is currently on long term care but we need to capture and understand the impact of this crisis with all groups - particularly those living with a dementia. Fiona rightly uses a Public Patient Involvement approach and highlights the need for individuals themselves to have a proper input in shaping future services coming out of this crisis.

I would suggest that you could mention that the majority of people living with dementia in Ireland are in fact living in the community. (I'm guessing that is the case, knowing that in the UK it's approx 2/3 living in the community).

Might you also include 'in the community' in the title?

Range of views

It is difficult to reference a range of views when writing up an account of a personal lived experience. As far as the reflective element is concerned it is rightly important that Fiona and Helen addressed the possible criticism of Helen of not fitting the 'typical' idea of a person with dementia. 'What's typical anyway?' asks Helen. Her eloquence and remaining skills do not make her experience and comments any less valid.

It may be worth heading off any further critique of the letter involving a conversation with only one person with dementia by making it clear that Helen's positions on the European front are because she no doubt carries with her the stories and experiences of so many of her peers with dementia, living with a range of abilities across Ireland. Some of the reflections in the letter are clearly drawn from the experience of others.

Further on in the letter, although they highlight a dearth of service provision, they rightly acknowledge community based initiatives that have worked or that still have potential, even if they are not so widely available across the country.

Statements and arguments

In the 4th paragraph covering Helen's own challenges around anxiety and isolation, there is a throw away 'people...may need constant reminding' because of forgetfulness. There isn't a reference to this and although it may indeed be true I don't think it needs to be there, given the strength of the argument and key points to follow around rural and technological isolation. (Unless of course it was something you have both seen or had shared in your broader engagement with people with dementia).

I think you are both right to correctly identify the threat of people with dementia being excluded and deprived of the opportunity to contribute to matters relevant to them. Would it be because of a blanket assumption of no capacity? I'm not aware of the law around capacity in Ireland. Are questions of capacity usually decision-specific? And if that is a basic right as you mention, where or from whom might this threat of exclusion come? It might be worth mentioning where and in what circumstances. (I'm thinking possibly close relatives, neighbours, local decision makers?)

Language

'As dementia progresses it can rob the person of their ability to ...' It is possibly a personal thing but the term 'rob' always feels a little too loaded to me in a negative way, when we spend so much time promoting the ability and remaining potential of people not that we don't acknowledge the pain of things. May I suggest 'As dementia progresses it can affect a person's ability to...'. Otherwise I felt the whole letter to be very clearly written. Not always the case in many pieces of work!

Recommendations and next steps

I really like what the open letter has done. This crisis has revealed a new marginalised group - those people with little or no access to technology and WiFi - as well as those existing marginalised people with dementia in the rural community. Many of these 'invisibles' fall in both groups, no doubt. Helen spoke of her own isolation too, giving top tips and flagging up some excellent initiatives.

I think to the call for more funding of community services, Fiona and Helen could have been more explicit in laying out (in fact re-emphasising what they have already covered in the letter) exactly what an 'eclectic continuum of care' might look like.

- People not realising they need help and how to use it rather than lose it - calls and conversations, virtual meetings and the peer support that that brings.
- The community call initiative to mobilise community support.
- A strategy to provide WiFi access and the provision perhaps of 'stripped down' devices that can be easily used and accessed by people in remote areas.
- A simple information sheet together with a human contact.
- Practice-based registries - inclusion of people with dementia on the chronic disease management programme registers.

As a reader, the message of scant financial resources and extremely patchy provision of post diagnostic interventions such as CRT, got me thinking about exactly what practical suggestions other than more funding might work. Helen had already mentioned the benefit of virtual meetings (I assumed with peers in the iDWG for example) so I drew from the letter this final recommendation:

- **much better use of the power of peer to peer support.** - This 'self management' approach was hinted at but not explicitly put forward and could come in the form of people with dementia using their own experience and skills to accompany others following diagnosis - either in a post diagnostic [course](#) or through shared learning and use of simple counselling type skills for example.

Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Yes

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

Is the Open Letter written in accessible language?

Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Dementia and user involvement.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 12 Oct 2020

Fiona Keogh, National University of Ireland, Galway, Galway, Ireland

Many thanks Damian for taking the time to review our letter. Your comments and suggestions are very helpful and we have addressed each of your comments and made changes to the letter as follows:

It is important to emphasise that most people with dementia in Ireland, as elsewhere, live in the community and we have included a reference to this at the beginning of paragraph 8.

Although Helen lives in the community, we decided not to amend the title in order to keep the scope of the letter inclusive. Some reports confirm that her experiences of anxiety and isolation are also relevant to people with dementia living in residential settings. As you note, although Helen is describing her own experience she is drawing on her conversations and interactions with other people with dementia before and during the pandemic. The text at the end of paragraph 3 has been included to reflect this. In this dynamic environment, the supports to Helen have increased as services became more attuned to how they might operate as the pandemic continued. A brief description of these additional supports has been added to the end of paragraph 6.

Statements and arguments

The reference to the need for 'continuous' reminding because of forgetfulness has been dropped but we have kept the reference to the need for reminding in relation to social distancing as this is something Helen is concerned about herself.

The comment in the first paragraph was one of a series of reasons as to why we need hear the voice of people with dementia at this time. The law on capacity has changed in Ireland to protect decision making for those whose capacity may be affected, although it has not been fully implemented as yet. While a consideration of capacity is important, it is not an issue we explore in detail within the limited scope of a letter format.

Language

We agree it is important to emphasise the ability and remaining potential of people with dementia. The word 'rob' has been deleted.

Recommendations and next steps

A summary of the suggestions and recommendations is very helpful and we have included this at the end of the letter.

Your point about peer support is really important – it is one of the main areas of support for Helen and we did not make that explicit enough. We are happy to emphasise the importance and potential benefits of peer support.

Competing Interests: No competing interests were disclosed.

Reviewer Report 01 June 2020

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Steven R. Sabat 

Department of Psychology, Georgetown University, Washington, DC, USA

This Open Letter, co-authored by a person living with dementia (HR-B) is important in shining necessary light on the situations faced by people living with dementia during the pandemic of the Coronavirus (COVID-19), the subjective experience of the lockdown, the needs that exist, and the support that would be helpful.

This focus is especially important because (1) great attention and resources have naturally been given to those ill with the virus, (2) there has been a focus on people living with dementia living in nursing homes, and (3) there was a need for resources and services, including diagnostic services, for people living in their own homes in Ireland before the pandemic that has been exacerbated ever since because of the need to "cocoon" which can exacerbate the social isolation and the accompanying stresses that are thus entailed.

Understanding the subjective experience of people diagnosed is of utmost importance for many reasons, not the least of which is the direction in which resources and services can be provided so as to help such people avoid having to live in nursing homes while maximizing the quality of their lives while living at home, where social and cognitive supports are extremely valuable. This Open Letter fulfills this need admirably.

The references are all proper and cited appropriately. There are no "differing opinions" in this area of which I am aware. There is one typo in the Abstract, in the sentence that begins with "Every aspect of our lives..." The word, "affects" should be "effects".

Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Yes

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

Is the Open Letter written in accessible language?

Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Alzheimer's disease and Dementia

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 12 Oct 2020

Fiona Keogh, National University of Ireland, Galway, Galway, Ireland

Thank you Steve for reviewing our open letter. Your comments have even more relevance as we begin to understand more about the impact of Covid-19 on people with dementia and other marginal groups.

The typo in the abstract has been corrected.

Competing Interests: No competing interests were disclosed.