

Lived Experience



Voices of older people on the COVID-19 Pandemic 2020



Lived Experience...Introduction

Older people around the world bear the brunt of the impact of the COVID-19 pandemic. In Northern Ireland, as elsewhere, statistics paint a stark picture:

- People aged over 65 make up 90% of all the deaths attributed to COVID-19
- People who were living in care homes account for over 50% of related deaths

The hardship, pain and loss experienced by older people, their family, friends and carers has been heart-breaking. Despite their resilience and self-sufficiency, older people have endured distress and anxiety about many aspects of their lives.

Reports early in the pandemic caused Age NI and others to ask questions about human rights. Were older people being discriminated against when it came to making tough clinical choices or getting access to healthcare and other services? Fundamentally, were the basic human rights of older people being protected?

Lockdown has compounded painful and intense feelings of loneliness for many older people and increased a sense of isolation for others. Many older people have been, and remain, cut off from family and friends, and some have become dependent on others. In a bid

to stay safe, carers (many older people themselves) started or increased their own caring for relatives who are older, disabled or living with a physical or mental illness. Some carers have taken on intense caring responsibilities, helping with personal care while continuing their own paid work.

Not all public health messaging and advice was clear. Everyone over 70 was advised to be cautious but not everyone was asked or needed to shield. Because of this public messaging, some older people may have endured greater restriction, isolation and loneliness than was absolutely necessary. Now, despite lockdown and shielding measures easing, many older people are fearful of coming out of lockdown.

Most of the support services and programmes Age NI usually provides involves being face to face with older people. From the start of the pandemic, demand for Age NI services increased and we changed our way of working and how we offered our services and support. Our advice line responded to many anxious calls from people trying to figure out how to carry on with daily life in very strange and different times.

Age NI moved from being able to welcome people to our day centres and wellbeing services, to talking on the phone and delivering support to and on people's doorsteps.

We launched a new Check in and Chat service with the support of the Commissioner for Older People (COPNI) to offer people friendly support calls; and we recruited more volunteers to help out, all working from home.

Staying in Touch, Listening and Learning

We moved a lot of our work into the virtual world. Zoom is now where we meet the staff and members of Age Sector Networks across Northern Ireland, as well as connecting with the Age Friendly leads in Councils. This helped us to stay in touch with local issues facing older people. We captured impacts of the pandemic, shared our experiences as well as the best practice and learning across all Council areas.

All Party Group on Ageing and Older People

The All Party Group on Ageing and Older People also met online on the theme of *A Safe Post COVID-19 Future for Older People*, which drew a large number of people to attend. MLAs and members of the public heard presentations from the PHA's Frailty Network, the Co-Chairs of the Age Friendly Network and the Chair of Age NI's Consultative Forum. Questions and discussion ranged widely across the needs and concerns of older people.

Lived Experience – the Consultative Forum

In normal times, the Age NI Consultative Forum (see below) meets every three months, spending several hours working together. During lockdown, members began to meet every week for an hour on Zoom, mindful of the need to keep in touch with each other and the fast-changing situation.



What we heard from them about their own and others' lived experience helped Age NI to share and focus on the main concerns and priorities for older people. Adding their voice to what we heard during phone and video calls has informed this publication, which reflects key concerns and experiences through four key themes:

- 1. Support, health and care**
- 2. Communication and connection**
- 3. Loneliness and isolation**
- 4. Grief and loss**

1. Support, Health and Care



The pandemic and lockdown forced changes to many of the everyday care and support systems older people depend upon. From getting out to shop for essentials to planned medical treatments, what was familiar and reassuring was at best disrupted, at worst completely stopped. Complying with guidance to shield or take extra precautions was a source of anxiety and distress for many older people.

It took time to mobilise alternative mechanisms to ensure that everyone had the support they needed. Local communities responded with spirit and compassion to the needs of the most vulnerable coordinating food banks, shopping and deliveries but this too brought challenges to keep everyone safe.

Staying well and healthy is a priority for older people, their carers and others supporting them through the pandemic and lockdown. Trying to stay safe indoors with reduced contact with regular support and connections has had a major impact on health and wellbeing. Many are enduring loneliness caused by absence and not being able to visit or see relatives. So many have been bereaved and suffered the added pain of having to follow lockdown regulations and social distancing.

What We Heard About Most...

Health and care

Restrictions on acute and community services made managing existing health concerns more difficult for many older people. Health inequalities were compounded during lockdown. Our reliance on having skilled frontline health and social care staff was clear for all to see.

Restrictions to visiting arrangements in care homes are challenging for residents, relatives and care home staff. Finding ways to protect everyone in a care home while also enabling contact, connections and visits are key to improving outcomes and quality of life for older people.

Ensuring that personal care at home continued safely was a cause of concern for older people, families and carers. Many older people remain fearful and anxious as lockdown eases. Some require continued support and access to services to help re-engage in active life.

Food and essentials

Shopping online or locally was a major issue in the early stages of lockdown. Getting the right food and essentials at the right time was a concern for many. How to pay for shopping and restrictions on using cash caused worry.

Local, creative responses demonstrated generosity and compassion towards older people and boosted a sense of solidarity within communities.

Community support

Older people lost purpose in life as volunteering and other civic duties halted abruptly. Loss of connections

to community and social networks increased feelings of loneliness and isolation.

Communities became hubs of valuable local information and their signposting brought confidence to older people. Opportunities for volunteering and inter-generational support grew and age sector champions emerged.

“I was a very active community volunteer and suddenly everything stopped and my world crumbled. Because I am shielding my options of support are not there and my purpose has changed. I have been thrown into an unknown world and **it’s easy to become a recluse and deteriorate very quickly.**”

“I worry more about dying from **no supply of food than the Coronavirus.**”

“I have phoned my pharmacist and can’t get through; the line is constantly engaged. My prescription renewal is due today and **I worry because I need my medication and the doctor surgeries are closed.**”

“I tried to place an online food order but I can’t get a delivery slot and I have no family, it’s worrying times and **I feel so alone and my independence is totally rocked.**”

“I didn’t know about the volunteer prescription delivery service as have my carer picking up one this afternoon. And we haven’t been out of the house or too well, so having **4 weeks worth of meals will help take off the pressure. Thanks.**”

“I could do with some information on local cleaners and carers who I could use and would appreciate any help you could offer. **When you reach 93 you need all the help you can get!**”

2. Communication and Connection



From the start of the pandemic and to cope with lockdown, accessing sources of clear, up to date information has been very important.

Being connected was essential for everything from health and safety to shopping and entertainment. Older people need reliable, trusted sources of information so they can make informed, safe decisions.

The need for social distancing means that the experience of communication during lockdown took many forms – both high and low tech. Many of us embraced video calls for the first time as well as talking to each other through barely open windows and across garden fences.

For older people, particularly those with hearing or sight loss, the challenges can be physical in nature - social distancing and the wearing of face masks can act as barriers to communication.

Connecting online is not an option for everyone. Finding out that access to some services has moved online has been a source of anxiety and added to isolation.

Most of the 35 coronavirus-related deaths in the UK have so far been people aged over 60 and with underlying health conditions.

BBC News, March 2020

What We Heard About Most...

Digital exclusion

Older people would like to access support and services online, such as shopping, but don't own a smart device or have access to the internet.

Trying new, online ways to stay in touch and active in interests was a novel and welcome experience for many older people.

Physical connection

Older people have concerns about using public transport for getting out and about again. They need reassurance that public places and spaces are safe and accessible and "good to go".

Older people want safe ways to get back to their interests and activities.

Public messages

Early media reporting used phrases that reflected ageist attitudes. News reports on numbers of people who had died regularly added that they were "elderly and with underlying health conditions".

It is important to recognise that not everyone over 70 is the same. Nor did everyone over 70 need to shield.

Unclear messages caused some older people more hardship as they isolated more than necessary.

Keeping connections and services local and at a community level won favour with many older people.

Barriers

Older people with reduced mobility, sight and hearing loss face additional barriers to communication and connection.

Older people were targeted by scams exploiting fears by offering COVID-19 related products and services for sale at inflated prices or dishonestly.



“ Thanks for the call. But if I didn't get out of the house (81 years old) I would go mad, **so it's all well telling us to stay in but I need to go out.** ”

“ I have no way of getting transport to a hospital appointment so **if there is anything you can do to help me I would really appreciate it...** ”

“ I'm 90 and most of my friends have passed on or moved away. **I'm sat here 24/7 with no one calling.** ”



3. Loneliness and Isolation



Older people are especially vulnerable to the effects of loneliness and it has been proven to have a significant and serious impact on physical, mental and emotional health.

Loneliness and isolation bring risks of frailty and cognitive decline so older people who were shielding feared losing their fitness and mobility levels.

During lockdown everyday routines were disrupted and social interaction and communication became a challenge. Many older people who were usually active in their families and community as supporters and volunteers felt the loss of this role acutely. Anyone not online was at a disadvantage with fewer opportunities to connect with friends and family.

The potential impact on mental and emotional health was significantly high for those with caring responsibilities and living alone. (ONS, May 2020)

80,000 older people live alone.

One in four older people live alone, and this increases with age.
Source (NISRA February 2018)

What We Heard About Most...

Frailty and vulnerability

Older people shielding and not able to maintain movement and activity lost physical and cognitive fitness rapidly. Reduced access and changes to services as well as fear stopped people from seeking healthcare support. Families also endured separation and absence and worried about older relatives in care homes.

Having a role model like Lady Mary Peters who launched the Age NI Move with Mary video series is greatly appreciated. She motivates older people and guides them on how to improve strength and mobility safely at home.

Family connections

Caution led families to make changes to caring arrangements taking on additional responsibilities causing isolation, anxiety and stress.

Lack of connection and being unable to visit care homes caused some to worry about the risk of abuse and neglect.

A regular Check in and Chat friendly phone conversation can bring significant benefits to older people and their families.

Mental health and wellbeing

Even the most resilient and self-sufficient older people have experienced confusion, fear and anxiety during the pandemic.

The challenge of following guidance while wondering fretfully about the future has impacted on people's mental health and wellbeing causing some to feel depressed. Ageist comments and messages have caused anger and upset.

Finding novel and creative ways of staying connected and supported helped older people to maintain resilience and keep a positive attitude.

“ I really appreciate **the human contact.** ”

“ I have been getting help from my son who has met my needs but it's lonely and boring having had to stay in during lockdown but I'm getting by... **thank you for taking an interest and for keeping touch over the past few months.** ”

“ Having the volunteer to talk to is like having a wee door; everything is stuffed inside and opening the door and **allowing some of it out helps me.** ”

“ I'm not a very chatty person but I'm happy enough to get calls as **I have lost a lot of friends as I have got older.** ”

“ I have outlived many of my friends and **become more isolated.** ”

“ Has really helped me, I would have low mood, on medication from GP, **on the days I get the calls I feel better.** ”

4. Loss, Bereavement and Grief



The COVID-19 pandemic is responsible for a significant increase in the number of excess deaths in Northern Ireland and older people feature disproportionately among them.

At its peak, people living in residential and nursing homes accounted for half of all the COVID-19 related deaths.

Vital infection control measures in hospitals and care homes meant that grief and loss were compounded for many older people and their relatives.

Mourning and funeral rituals have been curtailed beyond all recognition. Bereaved families and friends cannot comfort nor be comforted in the usual and traditional ways.

Talking about end of life is never comfortable nor easy. The pandemic forced more people to think and talk about the experience and expectations of death and bereavement.

These are without doubt challenging times, but it is crucial that we continue to protect people's fundamental human rights. The role and timing of advanced care planning has taken on particular significance.

There is a sense of societal grieving for the loss that so many have endured. People are seeking ways to mark this shared experience in a meaningful and timely way.

What We Heard About Most...

Advanced care planning

Families were distressed and concerned when advanced care planning and DNA CPR (Do not attempt cardiopulmonary resuscitation) forms were raised during the early stages of the pandemic.

Memorial

The bereavement and loss experienced by so many requires a response from wider society.

Missing the normal rituals of funerals and mourning calls for additional support in the community for those bereaved and suffering.

Care homes

People were worried and anxious about older people living in residential and nursing homes. Being unable to visit a loved one in a care home caused a range of feelings of heartbreak, loss and helplessness for both residents and families.

The shocking impact and death rate in care homes has increased understanding of the importance of quality social care and the need for change and improvement.

90% of the deaths related to COVID-19 are of people aged over 65. Source NISRA August 2020

“ My wife died three weeks ago and **I really appreciate the check in calls.** ”

“ A lifeline in these **uncertain times.** ”

“ The service has supported me as my mother died recently in England and I cannot attend the funeral. **Was lovely having someone to talk to.** ”

“ I worry I can no longer visit my mother in a care home and if it will be **the last time I see her.** ”

“ My husband has to go to respite and [Age NI] was able to give me information on the care home that he is going into and **reassured me.** ”

Action Points



Support, Health And Care

Shopping



Continue support for food and essentials shopping including priority delivery slots for vulnerable groups.

Family Carers



Recognise the key role played by family carers, ensuring additional support is available in a way that works for them and their loved one(s).

Food Parcels



Offer nutritional food parcels based on household size and dietary needs.

Step Up Social Care Support



As a matter of urgency, resume social care services, such as day care and respite, which were stopped during lockdown, ensuring support is in place for those requiring new or different help. Re-start domiciliary care packages where families provided this care themselves during lockdown.

Need For Cash



Ensure cash is retained as a payment option for those who prefer or need to use it.

Transport



Ensure transport is available and in place so that older people can get to and from appointments, community services, shopping etc.

Frailty



Address increased levels of frailty from lockdown/inactivity to support older people to regain their strength and confidence.

Health Checks And Treatment



Re-establish regular health checks, GP visits, hospital appointments and treatments to maintain health and prevent detriment. Continue partnerships between community pharmacists and local community and voluntary organisations on safe delivery of prescription medication.

Care Home Review



Commit to a robust review of what happened in care homes during COVID-19 so that those who live and work there and families can be assured of a better, more immediate and effective response to any future health emergency.

Safe And Compassionate Care



Provide assurance of good quality care in care homes, protecting older people who are particularly vulnerable to COVID-19 along and upholding their rights.

Valued Workforce



Prioritise and value the skills and key roles played by the social care workforce.

Parity For Health And Social Care



Recognise and resource social care as an equal partner in how we provide for the health and care needs of older people.

Action Points



Communication and Connection

Voice & Co-Design



Listen to the views of older people – they are experts in what matters to them. Develop and quality assure public health messages with older people. Nothing about us without us.

Local Links



Connect with and resource local communities to ensure effective signposting and on the ground support.

Going Digital



Ensure access to 4G networks across Northern Ireland. Support ownership and confident use of digital devices for older people.

Traditional Works Too



Ensure accessibility in communications channels – not everyone is online.

Action Points



Loneliness and Isolation

Loneliness Strategy



Develop and deliver on a Loneliness Strategy to tackle the significant and increasing levels of loneliness and isolation in Northern Ireland. Co-ordinate action across all levels of government and statutory bodies and within local communities.

Resource



Adequately resource frontline services that are focused on addressing loneliness and building personal resilience.

No-One Should Have No-One



We can all play our part - loneliness is everybody's business.

Action Points



Loss, Bereavement and Grief

Talking About Death

Build on insights to find timely, safe and compassionate ways to talk about end of life.



Support At The End Of Life

Support the delivery of collaborative and compassionate end of life strategies for an individual and their loved ones.



Planning Final Care

Start the conversation and follow best practice in advanced care planning.



Bereavement

Implement properly resourced bereavement support.



Action Points



Protect, Respect and Don't Forget

Protect

It will take a joined up, community-wide approach to protect, care and support older people wherever they live.

Respect

TREAT US AS INDIVIDUALS:

Don't respond to older people as a single, homogeneous group – there is a huge range of age, ability, needs, circumstances and interests.

DON'T DISCRIMINATE:

- Focus on the rights of older people and address ageism.
- Don't put in place "blanket" policies for older people.
- Put older people at the heart of planning for a safer future.
- Adopt and resource the Age Friendly ethos to planning and sharing best practice, creating inclusive and age friendly communities.

Don't Forget

The challenges facing older people, and the services they rely on, were brought under the spotlight by COVID-19.

As everyone adjusts to the new normal, don't forget that this new way of living is not the same for everyone. Older people have a voice. Challenges remain. With a renewed spirit of compassion and community, remember that everyone, no matter what their age or ability, needs clear information, support, connections with others and a helping hand from time to time.

Age NI Active in Crisis



Over the past five months Age NI has been active and agile in its response to the COVID-19 crisis which led to an unprecedented rise in demand for support from older people, carers and people living with dementia.

The sudden changes caused by lockdown included increased loneliness, disruption to routines, reduced social contact which, combined with existing poor health for many, led to poorer outcomes, affecting physical deconditioning and mental wellbeing.

Age NI's Rapid Response

- Our domiciliary and residential care services continued to deliver person-centred, safe care to the people we support.

- Our wellbeing and day care services changed how they worked, with older people being contacted regularly by phone to ensure they had all they needed.
- Our regional staff team were deployed to our advice line to deal with the four-fold increase in calls and to provide vital practical and emotional support.
- We established a new 'Check-in and Chat service' for older people who were isolated and lonely.
- We enlisted the support of over 170 new volunteers to provide regular reassuring phone-calls and contact.

Our Impact March – July 2020		
2,500+ people supported	18,970 calls and direct support	240 Volunteers
Feedback from Service Users	Feedback from Advice Callers	Feedback from Volunteers
79% Reduced isolation & loneliness	50% Ability to manage financially	97% Enjoyed the volunteering role

Keeping Well at Home

In order to support as many older people as possible who were shielding, Age NI worked with the Frailty Network NI, Public Health Agency, Age Sector Networks and Age Friendly Network NI to deliver vital resources and communications to help older people keep well at home during lockdown. The aim was to give older people the latest evidence and guidance to help them maintain their physical and mental wellbeing during lockdown and to know where there is support if they need it.

Led by Ambassador Lady Mary Peters, the 'Move with Mary' video series captured the headlines of major media outlets and the hearts of thousands of older people inspired by Lady Mary's rally to keep moving, connected and safe despite lockdown. The five exercise videos catered for every level of capability, ranging from simple seated stretches, to balance, strength and gentle aerobic exercises suited to older people

Aware that not all older people were online, we undertook a four week 'Keeping Well at Home' press campaign to support the Move with Mary video release and the launch of a 'Keeping Well at Home' booklet containing expert advice and real life stories around exercise, nutrition, mental wellbeing.

Age NI Community Appeal

To provide additional community support, Age NI launched a public appeal to fund more services and activities across the Northern Ireland. The public response to the Age NI COVID-19 fundraising appeal was swift and generous. In return, Age NI provided grants to support almost 2000 individuals through local age sector networks with their COVID-19 response.

The response by age sector networks was creative and practical:

- Well-being activity and entertainment packs
- Information leaflets and newsletters
- IT equipment Emergency funds
- Doorstep lockdown social activities
- Pre-prepared meals and food parcels
- Extended phone support services
- PPE, prescription and medication delivery

I have hope again. Age NI service user

The service really worked for me as I know that someone is there for me. Makes me feel less lonely. Age NI service user

It has been a very overwhelming time and we are thankful for the funds in this crisis. Age Sector Network Manager

The Voice of Older People



Consultative Forum at Age NI

The Consultative Forum is made up of older people who volunteer their time and expertise to Age NI. The role of the forum is to inform and influence policy and practice at Age NI and members ensure that the voices and needs of older people are reflected in decision making about their lives.

“...an invaluable, informed, representative and expert insight...”

Age Sector Networks

Age NI has helped build an infrastructure of independent age sector networks across Northern Ireland.

Age NI supports networks to share information and learning on key issues to strengthen the voice of older people and bring about positive change.

For information on local age sector networks contact

Elaine Curry
elaine.curry@ageni.org

Age Friendly Network NI

Age Friendly - an initiative of the World Health Organisation (WHO) - is developing and growing across Northern Ireland. There are Age Friendly leads in all Council areas. The Age Friendly Network NI brings together representatives from the eleven Councils, age sector networks and groups that work with older people in local communities to share learning and best practice.

Age NI supports the Age Friendly Network NI with the Department for Communities and the PHA.

For information on Age Friendly contact

Elaine Curry
elaine.curry@ageni.org



Visit ageni.org/movewithmary to join in.



'Check in and chat'

Contact the free telephone advice service for the over 60s on

0808 808 7575

Monday - Friday, 9am - 5pm or
email info@ageni.org



No one should be left behind

As lockdown lifts, you can help us make sure vulnerable older people aren't forgotten. Donate today to help Age NI open doors for our older generation

ageni.org/covidappeal

