



Telling it like it is:

what older people told us about
their experience of Covid-19, and
what Ireland should do about it



JULY 2021

“

**I can't meet my
friends, I can't go
to the beach, I'm
tied to the house.**

**Loneliness and
isolation, it's cruel. ”**

Foreword

The Alliance of Age Sector NGOs (the Alliance) represents the collective thinking of seven significant NGOs working in the age sector.

Separately, we provide vital services for older people, support older people to contribute to and participate in community life and advocate for better policies, services and supports for older people at national and local level. Together, we collaborate to combat ageism and to seek action on the specific issues

that make older people's lives more difficult than they need to be. We work together to support Ireland in becoming a better place in which to grow old.

Alliance member organisations have a direct line to a broad diversity of older people living in Ireland. We listened to them throughout the pandemic.

Many expressed gratitude for the protection measures that were put in place, and for the support and consideration that many communities excelled at. But they also voiced frustration, anger, worry and concern about the unintended or unforeseen consequences of the protection measures. As lockdown followed lockdown, it turned out that, for

many older people, and despite their resilience, the side-effects of Covid-19 – loss of confidence and capacity, loneliness, isolation, anxiety, depression – were and are as harmful as the disease, and perhaps more so.

From what older people told us, it also became clear that the pandemic set free the ageism that, equality legislation notwithstanding, is endemic in Ireland. We would suggest that if ageism had not been so prevalent, the effects of the

pandemic on older people would have been less severe. The experience of older people, as set out in *Telling It Like It Is*, has clear implications for future policy and practice in Ireland. The voice and lived experience of older people needs to be heard by those responsible for policy development and implementation. We call on decision-makers to listen and use these reflections to inform our recovery phase. Creating an Ireland that values older

people, warrants a whole of Government response which would inform future planning and service delivery across a range of entities: Government Departments, national and local statutory agencies as well as the Community, Voluntary and private sectors.

Covid-19 demonstrated that both older people themselves as well as the Community and Voluntary Sector will be critical partners for building back better.



“

Is this it now?

”

About Telling It Like It Is

At the time of writing, thanks to huge efforts from the population, the rollout of vaccines and Government action, Ireland is opening up again.

At the time of writing, thanks to huge efforts from the population, the rollout of vaccines and Government action, Ireland is opening up again. The talk is of “getting back to normal”, or a new normal, or a better new normal. We are encouraged to

stay vigilant but to “get back out there”. So off we go.

Is it as simple as that? Not for older people, anyway. The pandemic thrust older age into focus in ways that no-one would have imagined at the start of 2020, and not always in

a good way. Now that Covid-19 is being managed, there’s a danger that what Ireland learnt during the pandemic about the experience of older age and about ageism will be swept aside in the rush to ‘build back better’ and the Next Big Thing.

The Alliance of Age Sector NGOs (the Alliance) represents the collective thinking of seven significant NGOs working in the age sector, uniting our learning from working with a wide diversity of older people and the issues that they face. As such, we know that the Next Big Thing in Ireland is, in fact, ageing and older people. As the population ages and people live longer, and as older people make up an ever larger percentage of the whole, how we think about older age and older people will have a significant bearing on our future success, cohesion and happiness as a nation. The

kind of society in which we would like to age, living and dying in the place of our choice, being valued, having support and meaning in our lives – all are issues of enormous importance to everyone.

After Covid, we need to Build Back Better with older people. Not for older people, and certainly not without older people. Because older people, and the issues which affect them, are under-represented in political decision-making of all types, there is a real risk that they will be overlooked in the rush to reset. But no

country determined to Build Back Better can afford to ignore the experience, wisdom and creative contributions of older people. And no country planning for better and more equitable times ahead can afford not to plan for an older future, too.

Before we can get there, Ireland has to deal with the collateral damage caused by the pandemic and some of the strategies used to respond to it. The impact of the pandemic, the manner in which aspects of it were handled, and the response measures involved, had a

disproportionately adverse impact on older people's lives and wellbeing. Covid-19, and Ireland's response to it, illuminated inequality.

Older people talked to Alliance organisations about these effects throughout the crisis. The number of calls went through the roof: up to seven times as many calls as usual, for some of us, and the average length of calls quadrupled. Telling It Like It Is brings together:

- what older people told us during the pandemic

- what we observed
- what Ireland needs to do about it.

Telling It Like It Is contains little in the way of formal research and data. It aims to tell it like it is, directly, as we heard it from our staff, volunteers, members and older people themselves. Alliance members have plenty of reports, research and data to back up and flesh out the urgent messages it contains. We'll be very happy to supply them.



“

**Can't wait to get
back but how am I
going to be? I don't
know how to be the
way I was, feeling
useful in life.**

”



“

**I never felt old
until this year...
Now I am made
to feel my age as
vulnerable and
dependent.** ”

What we're saying... and what we're not saying

The Alliance is not interested in special pleading. The pandemic was hard for everyone.

The Alliance is not saying that older people are more important than other people. We're simply concentrating on their particular experiences. We're not interested in pitching older people's interests against those of anyone else.

The Alliance isn't saying that

all older people had the same experience of the pandemic, or that it was all bad. Older people were grateful for aspects of the Government's response, and for the intentions of public health experts. Older people were resilient, coped, adapted and managed. Some found new links to their communities, learnt

new skills, concentrated on what was most important to them. Many, however, found that the negative effects of the pandemic outweighed any positives. For those living in residential care, or who are themselves carers, along with those living alone or without digital skills, the experience of the pandemic was particularly tough.

The Alliance, and older people, are not looking for apologies. We all know that everyone in every walk of life did their best in circumstances which were new and frightening for the entire world. Nobody set out to exclude or demean or upset anyone. That some actions had unintended or unforeseen consequences was inevitable – but ageism exacerbated their effects.

We need to face up to the fact that some of the strategies used to deal with Covid seriously disrupted the social determinants of older

people's health and wellbeing by isolating so many from the people, activities, services and supports that keep them going and make life worth living. The side-effects of Covid-19 – loss of confidence and capacity, loneliness, isolation, anxiety, depression – were and are as harmful as the disease, and perhaps more so.

The Alliance is saying that older people, no matter what their health status, are active contributors to life. Blinkered views about "burden" are part of the problem and offer no route to a solution. In fact, older people are part of the

solution, not part of the problem; a valuable asset, not a drain on resources. "Solutions" which ignore older people's contributions aren't solutions at all.


Now is the time to reflect on and face up to what happened and how matters can be redeemed. The reflective aftermath of the pandemic presents the ideal opportunity to learn lessons and make changes towards creating a brighter future. Failure to act now will condemn all of us to yet more avoidable distress.



“

**I have fear of
being stopped
by the police
for violating
restrictions.**

”

A close-up profile of a woman with dark hair, looking down. The image is heavily overlaid with a red color gradient on the right side and a yellow/orange gradient on the left. The text is white and bold, with large quotation marks on either side.

**“ We can’t do
anything... We are
locked up! Locked
in! Locked out! ”**

The C-word and its toxic effects

Cocooning – a word which riled older people like no other – and protective attitudes towards older people, however well-intentioned, went on too long for most, and became unhealthy for many.

Healthy people are more likely to be happy, and happy people are more likely to be healthy. During the pandemic happiness fell off the table for many older people, affecting their health and wellbeing profoundly. For every older person who was relieved not to have to go out, many more felt constricted and restrained.

Despite this, older people were compliant. Nearly 70% of over-60s surveyed by TILDA reported leaving their homes less often than before. Nearly 80% didn't see friends. One in 20 said that a friend or family member had died due to Covid-19. What will be the long-term effect of all this on people in older age?

A pandemic response predicated largely on the suppressive potential of lockdowns and restrictions affected different ages, social classes and segments of society differently. Following are some of the effects on the broad range of older people, whether "cocooning" or not.

- **Older people died, disproportionately to others.**

Too frequently, their end of life wishes were not sought or honoured. Dying with dignity is the hallmark of a decent society.

- **Older people were bereaved, disproportionately to others.** Restrictions on the familiar rituals of funerals, bereavement and consolation caused deep distress that will reverberate for a long time. **Grieving in isolation was wretched.**

- Older people's **lives were disrupted profoundly, in ways that can't be remediated. Precious time was lost, that can't be regained.**

- **Older people living in nursing homes** were suddenly subject to rules about what was "allowed" and "permitted" in their own homes. Many were marooned in their bedrooms. Activities stopped. Visits stopped or were reduced to waving through windows. The risk of abuse or neglect grew. Being confined to bedrooms for reasons of infection control sapped residents' will and led to deterioration in physical and mental health and wellbeing. Many staff lacked the necessary skills training to support residents through dying, death or bereavement, compounding their distress. **Life became medicalised.**

- Older people whose relatives and friends live in care settings were **unable to visit** them properly for months on end. These restrictions, however justified, caused enormous distress.

- **Older people** living in their own homes were **restricted and frightened** into isolation. This weighed particularly hard on those who live alone.

"I have fear of being stopped by the police for violating restrictions."

- **Older people's** agency was all but annihilated. **Life became a series of instructions from elsewhere.** Some older people were reduced to donning disguises just in order to go for a walk.

"I sneak out early in the morning to a green area before I get caught and put back in my box."

- **Older people** who were the backbone of community volunteering found themselves **stripped of their identity** when their attempts to volunteer during the pandemic, for example, via the Community Call, were rebuffed. Being told that they were not able to volunteer during the pandemic was a smack in the face, a message that **their contribution was unrecognised and undervalued.** For most older people, this was ageism unmasked. **They felt that they were being "cancelled".** It's as yet unclear whether older people will want to return to

such unsung activities, or if they still have a place. Older people's voluntary contributions are not a tap that can be turned on or off without consequences.

"I volunteered locally to do the voluntary contact tracing and at first was accepted but then I mentioned I was over 70 and was told no, you can't do this due to your age."

- **Older people** who had been active and out there found themselves **thrust into the category of “vulnerable”**, “dependent” and in need of “protection”, undermining their confidence and self-esteem. They reported that **they felt “old” for the first time**, and could feel themselves ageing and disengaging, week by week. They now fret that they will be disrespected if they go back out into the world, having discovered for the first time how negatively “age” is routinely viewed.

“[The pandemic] made me think about how dependent I will

be on others in a few years. I didn’t like it and I could have done without the reminder of how “outside” of society older people can be made.”

- Active older people were **forced into passivity**. Anger gave way to indifference and languishing. Anger creates energy, passivity saps it. Many older people feel let down and disappointed, and have internalised the notion that others are more important. By the third lockdown, **many had stopped engaging**.

- **Older people** sensed that they were **becoming deskilled**, for example, saying that they would need driving lessons before going back out on the road. It takes time to regain lost confidence.

- **Older people** were **financially compromised**. Workers aged 66 and over are ineligible for pandemic support payments. Being at home more led to higher heating bills. Some turned to private service providers to make up for the withdrawal of home care supports. Alliance members set up schemes to deal with these and other financial issues.

- Older people's **social contacts were decimated** by the closure of clubs, cafes and other activities, compounding loneliness and isolation. Some, run by older people themselves, may never reopen. Some older people fear that they have **lost their capacity for sociability**.

"A lot of... members [of an older people's organisation] are absolutely terrified out of their wits. Because of coronavirus they really don't want to have contact with

anybody, they don't want to meet for a coffee, they are just totally confined to their house...very, very nervous... extremely nervous."

- **Older people's health deteriorated** when they were unable to access essential appointments and procedures. Everything from the renewal of public services cards to the continuation of cancer treatment and assessment for vital home adaptations was disrupted for months on end. Alongside that, older people cancelled medical appoint-

ments, citing fear as the main reason. **The backlog in services will cost lives** and there is every chance that the system will be overwhelmed by pent-up demand and need.

"A year is too long not to have blood pressure etc checked, and can only lead to problems/ill-health further down the road."

"The pandemic bated the confidence out of people."

- **Older people** who rely on community healthcare and other services became anxious and bereft when those **services were withdrawn or reconfigured**. Life got a lot harder.
- Older people's confinement led to the **acceleration of pre-existing conditions**. Many lost physical and mental capacity. For many, their world has become a smaller and more frightening place.

"Going around the garden in circles is depressing."

- Older people became **depressed**. During the pandemic 1 in 5 over-60s reported clinically meaningful levels of depressive symptoms, and nearly 30% reported high levels of stress. For some older people online engagement helped; for others, **getting out of bed and getting dressed was an achievement**.

"I have become more introverted and have lost my sense of hope. There doesn't seem to be light at the end of the tunnel."

- Older people who were diagnosed with life-limiting conditions during the pandemic were **unable to access the range of supports** which would normally have been available. The longer-term impact of this is likely to be severe.
- Older people had a sense of losing relevance, of **not being trusted to make decisions** for themselves. They wanted to make their own decisions about self-isolation.

"Leave us with the flexibility to use our common sense to keep away from danger."

- **The positivity in many older people's lives evaporated** during the pandemic. Getting it back could take a long time. Connection and social engagement are the bedrock of positive ageing, but these were fractured during recurring lockdowns. The older old, those living alone and/or offline were particularly affected.


"Seniors are slowly being "strangled" by daily warnings of how vulnerable they are, thus paralysing them into inaction."

- New retirees had nowhere to turn. More than a year of **potential social capital may well be lost** now.
- The pandemic brought some older people closer to their families, offered more time to concentrate on hobbies and "things that matter". On the other hand, some older people found themselves "controlled" by relatives, with further **loss of autonomy**.
- Some older people tapped into **reserves of resilience** which enabled them to endure, although this had worn thin by the third lockdown.

"With the Covid-19 virus I've had to cocoon myself but that's OK, I'm surviving.... You can get used to anything."

The pandemic faced many older people with the spectre of future fragility, while intensifying the marginalisation of others. People are bereft, and fear was a logical response. We need to offer appropriate ways for older people to process what happened to them during the pandemic. **We don't know what we have not heard, and what else we need to hear.**

"Covid robbed us of precious time."



**“ We cannot
carry on losing
valuable time.
At our ages, our
time is limited. ”**

None of this was inevitable...

Like everyone else, **older people understood** the importance of protecting themselves and other people.

What they largely didn't appreciate was the fear and diminishment that accompanied this package.

The sad fact is that it need not have been like that.

The National Positive Ageing Strategy (NPAS), published in 2013, has been waiting for Government to dust it off, update and refresh it and

take it seriously. Had it been implemented in the seven years between publication and pandemic, many of the negative effects on older people of the Covid-19 response could have been avoided. NPAS contains still-relevant approaches to eliminating ageism, ensuring that ageing is taken seriously, that older people's needs and preferences

inform policy and practice, that most older people can age in place, get the supports they need, have options in their lives and can participate fully in all that's going on. Is the lack of urgency itself a manifestation of institutional ageism? What has made implementation so problematic?

When it was published in 2013,

NPAS aimed to create a “shift in mindset in how we, collectively and individually, conceptualise ageing”. The vision is as valid as ever. **What we need is a Government champion with a cross-Departmental brief who takes responsibility for focussed progress on tackling ageism** and making the NPAS vision a reality.

For more about NPAS see Appendix 3.

Only Government can bring together all stakeholders and ensure best quality collaboration. We need to see leadership and coordination, systematic engagement and real commitment, energetic implementation and meaningful monitoring.

We all need these things, because **failing to take older age into account is literally self-defeating**. What kind of life do YOU want as you get older?

Older people's contribution is essential for post-Covid national recovery

Ireland's growing older population constitute an engine for recovery, not a drain:

- Before the pandemic more than 75,000 people over 70 volunteered each week (Tidy Towns, Meals on Wheels, St Vincent de Paul, charity shops, community events...) and over 200,000 every year.
- Older people are major spenders on domestic tourism and hospitality.
- Half of older people provide

financial assistance to their children. That contribution was vital during the pandemic as families struggled on reduced incomes and with growing demands.

- Half of older people keep their children in the workforce by minding grandchildren.

Older people's contribution is an investment: over 70s who engage in social activities, volunteering, childminding etc report significantly better quality of life than those who don't.

Healthy and happy older people cost the State less.

The rhetoric of older people "being a burden" is a clear example of the endemic nature of ageism, and the lack of recognition of their contribution, both formal and informal, in society. Retired health workers volunteered during the pandemic – where was the big message about that? And who can quantify the benefits that come from intergenerational relationships?

Meaningful engagement with older people

As society starts to reset for the future, there is a big danger that older people will be left behind, associated with the problems of the past, rather than part of the solution to be developed. The reality is that older people are as much part of the solution as anyone else. Given their experience and resilience, they have a lot to contribute, and a lot to say.

Older people are a vital and growing part of the population. Older people are not a passive category to be minded and looked after and done to. Older people are active citizens, not

passive recipients – or, at any rate, they would be, if human rights were really the driving force of Irish attitudes.

Ireland has to start having open and honest national conversations about ageing which don't shirk the issues or sweep ageism under the carpet of good intentions.

To Build Back Better, Ireland has to tackle ageism and its egregious effects on the lives and wellbeing of older people. To Build Back Better, Ireland needs older people's contributions and ideas. Best quality ways forward

depend on real social solidarity and everyone's contribution. Diversity of standpoints creates robust outcomes.

New forms of consultation proliferated during the pandemic, and are still growing. For all their obvious shortcomings, in some circumstances Zoom and its rivals have opened up new possibilities for older people, particularly in relation to participation and offering opinion. It's simpler than ever for Government to involve older people in policy development and decision-making.



“

**I think it's important
that an online option
is maintained as
face-to-face events can
be difficult to get to.**

”



“

**Learning to Zoom
was a challenge
we enjoyed**

”

Gains to maintain

In amongst the losses, the pandemic led to some rapid and positive developments, which we need to hold onto and develop further. For example:

- Many older people who were lonely and isolated before the pandemic were somehow connected during it. Older people previously considered “hard to reach”, for whatever reason, were reached and linked to their local communities in simple but profound ways. We need to make sure that

they are not lost again in a rush to regain “normal” life. There may be a role for reconfiguring Community Call structures to provide local intergenerational social engagement, especially for the older old and those who are fearful of re-engagement.

- Older people previously dismissed as uninterested in digital communication, or unwilling to engage with it, were galvanised into the brave new world of Zoom and WhatsApp. The digital

divide shrank a little, and is ripe for further narrowing, with (for example) public libraries about to introduce digital training for older people. Older people should be central to any plans to increase digital literacy and access. It's lack of familiarity, not stupidity, that holds older people back, along with the cost and availability of broadband (not everyone can race up the hill to get a better signal). It's pure ageism to say that older people are incapable: they just need the right supports.

“The help from [name] on the phone talking me through how to do it and encourage me to take part made me feel very involved. She had the patience of a saint.”

- Older forms of communication – telephone, the postal service – were rediscovered, benefitting older people greatly.

“We have contacted [peer-led group members] by phone and talked them through some easy exercises to keep them active.”

“All older people should have access to the internet, as a means of keeping in contact with the outside world.”



What older people want

On the whole, older people felt left behind and left out as opening up began to dominate the agenda.

What older people want is generally simple – connection, friendship, dignity, choice, support – ordinary aspects of the human decency that Irish people pride themselves on. During the pandemic, public health concerns and

bureaucracy sometimes got in the way of ensuring that saved lives were lives worth living.

Ireland now needs to create the conditions in which older people can regain their energy and purpose. The vaccination programme is only part of the answer. Many older people have lost confidence, lost partners and loved ones, lost more than a year of their usual freedoms and independence.

In summer 2021, some are up and at it, determined to get their lives back and to have a good time before anything else awful happens. Many more are hesitant and uncertain, their confidence, ability or will damaged by their experiences.

Are older people's views being sought, heard, acted upon?

Reopening and returning

The relentless negative messaging that stressed older people's vulnerability and the dangers of "saying boo to a goose" resulted in compliance but also created high levels of fear: fear of the disease, fear of meeting others, fear of going out, fear of public transport... Even now, social distancing and dire warnings to be vigilant add complications to daily life and make planning a big headache. As older people try to regain their lives, the start-up costs – human and financial – will

be substantial. For example, renting venues large enough to accommodate a fitness group with social distancing costs more than the smaller places that were appropriate before the pandemic. Renewing lost enthusiasm requires nuanced investment of a different kind.

"Cocooning" saved lives in one way and may cost them in another. "Cocooning" resulted in less physical activity, increased stress and anxiety and lowered sleep quality. Loss of muscle

function and increased weight are likely to result, in due course, in more falls and fractures, more cardiovascular disease, lower quality of life, less confidence and, ironically, more vulnerability to diseases such as Covid-19. "Cocooning" reduced many older people's mental stimulation, too, leading to withdrawal, fear of activity and loss of capacity. Many older people felt that, with little time left to live, precious time was being wasted and could never be replaced.



Loneliness

Early in the pandemic half of all people aged 75 or more had never used the internet. While the digital gap may have narrowed a little in the past year, it was the very people who had to isolate themselves the most who had the least chance of mitigating that isolation through the use of online resources. **Life moved online; many older people were shut out.**

During the pandemic, **rates of loneliness doubled** from the previous year. Loneliness has negative effects on physical and psychological wellbeing. It also has financial

consequences, and not just because of increased call on medical services. Looked at the other way round, British researchers have shown that for every £1 spent on preventing loneliness, there are £3 to be made in savings.

The Roadmap for Social Inclusion and the Programme for Government both promise to tackle loneliness and isolation. A fund was announced in 2019 but its status is unknown. The report of the Loneliness Taskforce is still “under consideration”. The pandemic has shown the urgency of moving on these issues, now.

“

**Ageism...denies people
their human rights and
their ability to reach
their full potential.**

”

**António Guterres,
UN Secretary-General**

Ageism

Ageism refers to the stereotypes (thinking), prejudice (feeling) and discrimination (action) directed towards others or oneself, based on age. Not all of it is deliberate: unconscious bias in relation to older people pervades Irish society, even turning up in the recent Ombudsman's report on people under 65 living in nursing homes.

Before the pandemic, and equality legislation

notwithstanding, ageism was endemic in Ireland. As with so much else, it was lurking, almost unnoticed, in plain sight, until the pandemic set it free. It can even be found in professional training for people who work in the age sector.

Ageism is institutionalised throughout services, systems and society. It pervades everything – it, too, is a virus.

Ageism is everywhere, not least because it is so embedded that it feels almost “natural”.

Yet it has huge consequences on all our lives, and costs us all a fortune. Among its effects are poorer quality of life, health and wellbeing. The devil of unintended consequences is in the detail. A small example: removing seating from shopping centres as an infection control measure effectively put them off limits for people who need to take a rest while doing their messages, as well as taking away a valued simple way of connecting with others.

Lumping all older people into the same category, imagining that they have the same needs, is an obvious manifestation of ageism. Assumptions are everywhere: about what older people can and cannot do, are and are not interested in, want and don't want... Replacing the stereotype of the little old lady with one of the hang-gliding granny is no advance. Identity politics is as relevant to older people as any other group. Older people are as diverse in their thinking, interests, identities and realities as the rest of the population. Not every older man is a GAA fan or wants to join a Men's Shed...

Stereotypes are self-fulfilling prophecies, limiting older people's self-concept and view of their own capabilities. Covid-19 undoubtedly posed a greater threat to older people than to most other groups in Ireland, and rapid, decisive action was needed. But, after the first crisis-driven actions, more nuanced messages and guidance could have prevented some of the experience of marginalisation of older people, based on chronological age. Messaging about the threat to older people may also have encouraged others to feel that once they were safely tucked

away, the main danger to the population was sorted. The ageist narrative occupied space in the Twittersphere and elsewhere.

"Cocooning", as a concept, played into the already prevalent notion that older people are a vulnerable, frail group, whose need for protection and care sets them apart from the rest of Irish society. This message, both overt and subtle, riled older people, while at the same time sapping their confidence. **Many older read cocooning as being put in their place, with a bitter clarity as to what that "place" is.**

Listening and engagement were replaced in the pandemic by paternalism and “being looked after”. No matter how genuine and kindly meant, this message of “stay inside, we’ll mind you, we’re doing this for your benefit” undermined agency, and rankled. Once “tucked away”, older people were expected to be “grand”: grateful, compliant, obedient and passive. Older people got nervous about being chastised for breaking the rules and doing something “wrong” (“What are you doing, going outside and putting yourself in danger?”).

Chronological age was a crude instrument, and using it as the only criterion for physical isolation measures was discriminatory. It lumped older people together, failing to take account of diverse capacities, needs and personal situations.

“Cocooning” and related measures, such as the ban on nursing home visits:

- magnified social exclusion and anxiety
- sent loneliness and social isolation through the roof
- by limiting opportunities for exercise etc, made it much harder for older people to invest in their own health

- by limiting access to healthcare appointments, led to the deterioration of pre-existing conditions, harmful delay in reporting new ones and yet more anxiety about both.

In 2016 45% of people aged 50 and above said that they felt discriminated because of their age. How many would say it if asked today?

It’s in everyone’s best interests to change the narrative and tackle it, once and for all. Irish government policy on positive ageing posits combatting ageism “through awareness campaigns and by

encouraging the media and other opinion-making actors to give an age-balanced image of society". That would make a good start.

It's ageism which burdens society, not older people.


Covid-19 appeared to imprison ageing issues almost totally within the health ambit, as well as amplifying concentration on "vulnerability" and "need",

sweeping aside issues of agency, involvement (such as volunteering) and contribution. In fact, this compounded the challenge. Corralling older people's issues into the health sector alone is itself a system of marginalisation.

For more on the definition of ageism, see Appendix 2.

“ What is needed is a forward-thinking, rights-based approach that addresses underlying societal, legislative and policy structures that support long-standing assumptions about age. ”

**António Guterres,
UN Secretary-General**

A photograph of an elderly woman with short, curly white hair, seen from the side, washing a carrot in a kitchen sink. She is wearing a floral patterned shirt. The image is overlaid with a semi-transparent blue filter. The quote is written in white, bold, sans-serif font, with large opening and closing quotation marks on either side.

**“ I feel Covid can now be
used as an excuse for
a system that does not
support people to live
and die at home. ”**

Ageing in place

At the time of writing, housing has become a most pressing national political priority, and it is likely to continue in this role for some time to come. Innovation is in the air. In theory, 15-minute communities will support older people's continued independence by bringing amenities and transport within reach (despite the fact that the aspirational drawings always seem to centre on 20-somethings riding bikes or relaxing outside cafes). **Appropriate housing with supports for older people is part of the national solution,**

and must be treated as such, as important as schemes for first-time buyers.

Research report after research report has reiterated how most older people want to stay in their own homes and in their local community for as long as possible and, preferably, to the end of their lives. The current policy structure means that, for many older people, nursing homes are the only real alternative to one's own home when the latter is no longer suitable. Dependency and passivity are implied in the very

term "nursing home" or "care home", and many older people see them as a place of last resort or endgame. "Nursing" and "care" seem to most older people to trump "home" in the concept and in lived experience.

Whether or not this view is accurate is not the point: older people **are ever warier of congregated living**, and less likely to agree to or thrive in it. Covid-19 showed that **congregated settings can be more dangerous than staying at home with support**. Among

older people and their families, the high incidence of Covid-19 in care homes has served to create an even greater aversion to congregated settings. The language of “going into” a nursing home – not “going to live” there – speaks volumes.

There’s nothing new about supporting ageing in place. Many European countries abandoned congregated setting decades ago or have ambitious plans for change. Successful Irish pilot programmes have issued reports. The Government’s

official ambition since 2011 has been to facilitate community living for all people with disabilities – regardless of age or type or severity of impairment. The UN Convention on the Rights of Persons with Disabilities, which Ireland has ratified, recognises institutionalised facilities as a violation of human rights.

Yet bio-medical approaches continue to dominate, older people are not systematically involved in the planning or review of their own care and support services, and assisted decision-making is still not fully

enacted. Ireland has legislation entitling older people to live in nursing homes but not to enable them to access flexible supports to live at home. In 2019 the Housing Agency found that supporting older people to stay in their own (or in purpose-built) accommodation suited to their needs would save significant amounts of public money. But still nothing happens at scale.

Care in the home

Successful ageing in place depends on the seamless availability of meaningful, flexible, timely, person-centred home support services for those who need them. Shortcomings in the system mean that many older people remain at home only through the caring activities of family members, whose work multiplied during the pandemic when homecare services were reduced or withdrawn due to safety concerns.

The pandemic exposed the low value put on home care in Ireland. Yet supporting older people to remain independent

and connected improves wellbeing and, ultimately, reduces demand for other, more costly services. Investing in older people's health and wellbeing with services centred on maintaining independence and agency is a win-win situation all round.

More coherent, joined up, reliable services, responsive to older people's evolving needs, and delivered by skilled, valued workers, are essential to enabling more older people to age in place and to "live well to the end". The pandemic put health and social care workers through the wringer. In

particular, it exposed the low priority put on pay, training and conditions for nursing home and home care staff, and the effects of lack of preparation for intense levels of death and bereavement. Investing in professional support and quality training throughout the sector will result in a better quality of living and dying for older people.

The proposed statutory homecare scheme must meet social as well as medical need. It's essential to ditch an overly medical focus and take a social model approach.

"My...volunteer takes me out for a walk, chats to me and makes me a cup of tea. I really appreciate that and I hope it continues for the rest of my days."

The effect on carers

Some of the older people served by Alliance member organisations were in receipt of substantial levels of care when the pandemic began. Very soon, statutory and some voluntary services were reduced or cancelled, for health and safety reasons or because of redeployment. As a result, unpaid and informal carers, often family members, had to shoulder ever more responsibility, often with minimal support, for over a year. **Many carers are themselves older people:** some 15% of informal care is

provided annually by people aged 65 and over. As the pandemic progressed, more and more older people took up caring duties and spent more time in that role, often to the detriment of their own health and wellbeing. Becoming a new carer is known to be associated with deteriorating mental health, particularly higher rates of anxiety and depression.

Only now is the full impact of the pandemic on carers starting to be realised. The vast amount of care and domestic work that

(mostly) women do in the home and community formed the largely unsupported backbone of the Covid-19 response. **Older women experienced the cumulative disadvantage of undervalued care.**

Recent reports have highlighted the devastating consequences of this untenable situation, which led to deterioration in the mental and physical health of both carers and those they were supporting. Many described themselves as “broken”. An Alliance

member found that 40% of family carers reported a decline in their physical health during the pandemic, while more than half reported a decline in their mental health.

Four out of five family carers also reported a decline in the person they care for, as less stimulation brought about irreversible cognitive impairment and harm to people with certain conditions. This situation calls for urgent action.

Information

Information was vital in the pandemic. Many older people don't use websites for information, and were often confused by the frequent changes, mixed messaging and general information overload. Constant speculation about new variants and possible vaccine side-effects added to fear, along with a gnawing anxiety that there would never be a return to "normal", that being institutionalised at home would go on indefinitely, or that it would be just too hard to come out again.

During the pandemic, many GP and other health services went online. That shut out many of the older people who needed them most. New IT users were more likely to fall for online scams.

Along with the efforts of Alliance NGOs, television, national and local radio, local newspapers and peer-to-peer contact are trusted media which reinterpreted Government messages in straightforward ways, and worked best. Clearer, unambiguous, easy-to-understand health messages

would cut out the need for reinterpretation.

Huge resources went into ensuring that older people got the message to stay at home. Now a similar effort is needed to make sure that they re-enter society as fully as before.

"Stop the media terrifying the elderly. People are petrified of their neighbours almost."

Dying, death and bereavement

Covid-19 raised issues about where it's safe to live and die, the quality of end-of-life care, human dignity in dying and how best to support grief. Fear of dying and death fuelled the stresses older people experienced during the pandemic, particularly deep concern that their wishes, choices and beliefs would not be respected and that they would die alone. Those who lost loved ones experienced a

largely hidden anguish of not knowing how a loved one died, whether their end-of-life wishes were honoured and their dying dignified. Indeed, an Alliance NGO felt it necessary to issue guidance entitled "What can I do when I can't visit a loved one who is dying?"

The absence of consoling bereavement ritual and the lack of acknowledgment of loss, particularly in relation to

non-Covid deaths, was very distressing for older bereaved people. In general, older people's bereavement needs were forgotten. They lost friends, partners and relatives, and were isolated throughout both the dying and the bereavement process. The long-term effects of disrupted and delayed bereavement are, as yet, unknown. We are in uncharted waters.

“

**When my mother was dying
only one family member
was allowed to visit her for
30 minutes each day. I had
travelled a long distance
to be with her and was not
allowed to see her.**

”

What Alliance NGOs learnt about themselves during the pandemic

Alliance NGOs stay close to older people and hear their issues. This trust gave us a hotline to how older people experienced the pandemic. Telling It Like It Is sums up what we were told.

Alliance organisations transformed services and ways of working in a heartbeat, surpassing our expectations of ourselves and broadening our reach exponentially. We were surprised by our own agility. Some of us were able to introduce major new

services and information hubs within a fortnight, eliminating waiting lists and extending our reach. Others sharpened their focus to a diamond point.

We found new ways to do new things, as well as repurposing old things. We found new ways of connecting with older people and meeting their stated needs. The future looks hybrid, with a creative blend of online and in-person communication, activity and service delivery, enabling

more people to be reached and a greater diversity of needs to be satisfied.

We noticed the extent to which we were relied upon to create agile and appropriate responses to older people's stated needs. Alliance NGOs stepped up to the plate, at considerable cost to reserves and to staff energy, as we redeployed staff and volunteers. All hands raced on deck: collaborations were set up almost instantaneously, with statutory services and with other NGOs. We showed

ourselves and everyone else just what is possible when circumstances dictate huge effort.

Now we need to balance the pressure of a crisis with the long-term need to sustain. We can go on performing at a high level only if we are funded, consulted and involved as meaningful partners in wider society and, critically, if older people are consulted and involved, too. Without this, Ireland will be forever playing catch-up with demographic change.

Appendices

Appendix 1: AASNGO

The Alliance of Age Sector NGOs (AASNGO, the Alliance) represents the collective thinking of seven significant NGOs working in the age sector, uniting our learning from working with the diversity of older people and the issues that they face.

Separately, we provide vital services for older people, build the capacity of older people to contribute to and participate in community life and advocate for better policies, services and supports for older people at national and local level. Together, we collaborate to help Ireland become a better place in which to grow old.

- Active Retirement Ireland will reach out to all older people to stop loneliness through friendship and support.
- Age & Opportunity: Our mission is to enable the best possible quality of life for us all as we age.

- ALONE; Supporting older people to age at home.
- The Alzheimer Society of Ireland: Our mission is to advocate, empower and champion the rights of people living with dementia and their communities to quality support and services.
- Irish Hospice Foundation; Our mission is to work towards the best end-of-life and bereavement care for all.
- The Irish Senior Citizens Parliament; Working to promote the voice of older people in policy development and decision-making
- Third Age; Responding to the opportunities and challenges of ageing in Ireland.

Appendix 2

According to the WHO (Global Report on Ageism, 2021), ageism has:

- three dimensions: stereotypes (thoughts), prejudice (feeling) and discrimination (actions and behaviour)
- three ways of manifesting: institutional, interpersonal and self-directed
- two forms of expression: explicit (or conscious) and implicit (or unconscious).

Ageism is based on a culture's stereotypes and prejudices, and arises when age is used to characterise and divide people in ways which are unjust and lead to disadvantage. It pervades Irish society, with far-reaching consequences for health, well-being and human rights.

Appendix 3: About the National Positive Ageing Strategy

Published by Government in 2013, the National Positive Ageing Strategy (NPAS) aims to create a “shift in mindset in how we, collectively and individually, conceptualise ageing”. It sees itself as “the blueprint for this planning – for what we can and must do – individually and collectively – to make Ireland a good country in which to grow older in the years ahead”.

To achieve this, NPAS posits a whole-Ireland approach that pulls together central and local government, national and local statutory bodies, the community, voluntary and private sectors. NPAS goals encompass expanded housing options, accessible health services, enhanced opportunities for participation and contribution to Irish life at all levels, tackling the ageism that holds us all back, improving information provision and ensuring that older people's own priorities and ideas form the bedrock of thinking and action about older people's lives.

NPAS contains still-relevant approaches to eliminating ageism, ensuring that ageing is taken seriously, that older people's needs and preferences inform policy and practice, that most older people can age in place, get the supports they need, have options in their lives and can participate fully in Irish society.

Appendix 4: a note about sources

Telling It Like It Is is drawn from Alliance organisations' conversations with older people, and with staff, volunteers and members along with reports and research undertaken during the pandemic. Telling It Like It Is also draws on:

- National Positive Ageing Strategy (Dublin, 2013)
- Various reports produced by TILDA (the Irish Longitudinal Study on Ageing, Trinity College, Dublin, 2020–2021)
- WHO Global Report on Ageism (WHO, Geneva, 2021)

Maureen Gilbert compiled this account on behalf of the Alliance of Age Sector NGOs.



The development of this publication was made possible thanks to funding provided by The Community Foundation for Ireland.

