Crowded Isolation and Loneliness:

A Perspective from Carers of People living with Dementia

> I wish people would make the first move as I now find it extremely difficult.

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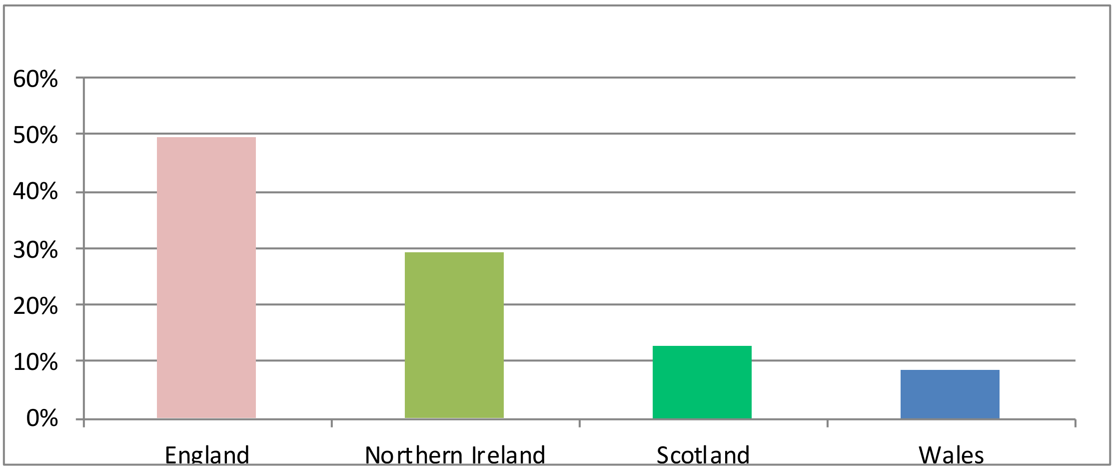
Appendix A

Equality and Diversity Data from the Online Survey

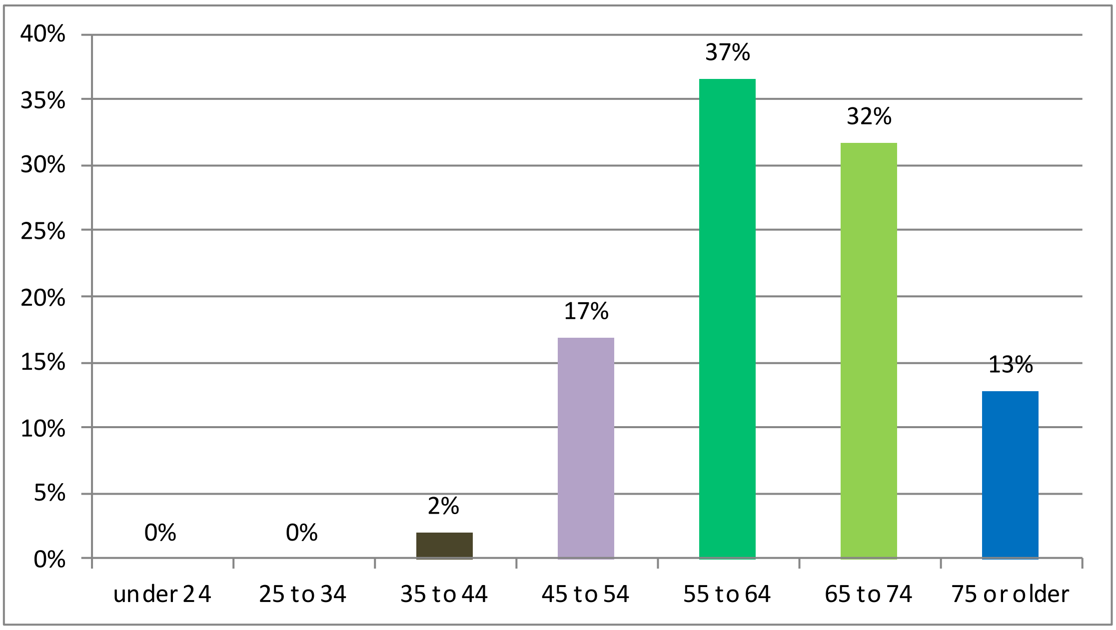
This was a 'convenience sample' drawn from tide members and those who received the invitation to complete the survey from partner organisations.

103 carers responded to the online survey. There were 22 questions in total. Of these, 10 related to the topic of crowded isolation and loneliness, 1 related to tide membership, 1 to further involvement, and 10 related to diversity and equality.

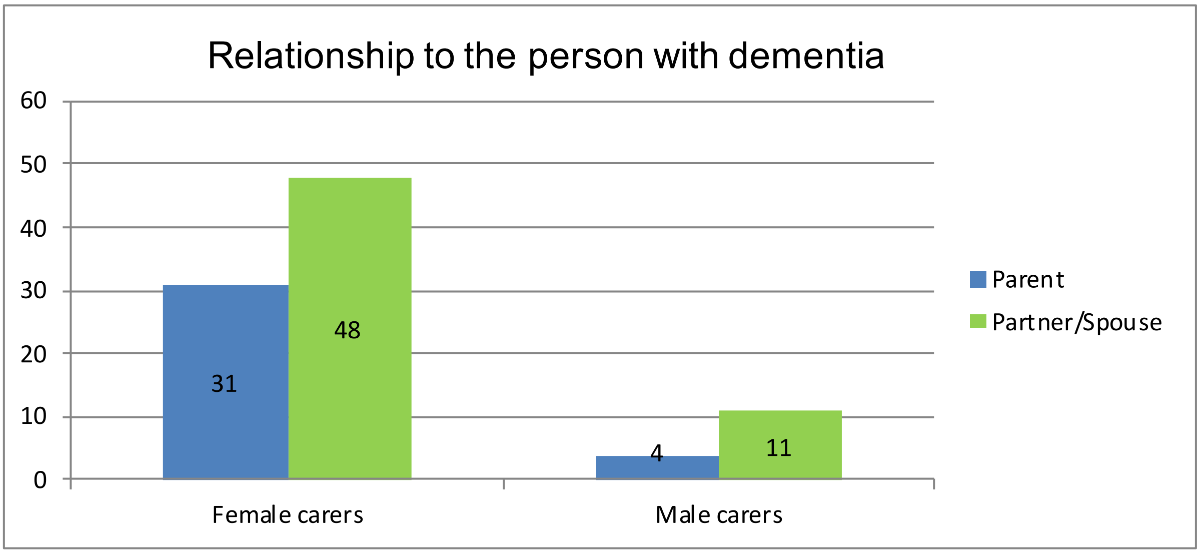
Where they lived: 49% of the respondents lived in England, followed by 29% from Northern Ireland, 13% from Scotland and 9% from Wales.



Age: The age range of the respondents is shown in the chart below. The majority are aged over 45, with the largest group aged between 55 and 64 years. The largest group being aged between 55 and 64 reflects the Census results of 2011, which reported that 1 in 5 people aged 50-64 are carers (ONS, 2011). Although older carers aged 85 and over are most likely to be a carer for someone living with dementia (Carers UK, 2019), this was not reflected in respondents to this survey.



Cared for: Of the 103 people who responded, 85 (83%) said they were current carers, and 16 (15%) said they were former carers. 43% of female carers and 4% of male carers were caring for a parent. The NHS Information Centre Survey for Carers in Households found that most carers (40%) care for parents or parents-in-law; over a quarter (26%) care for a spouse or partner; 4% for grandparents; 13% for disabled children (including adult children); 7% for other relatives; and 9% for a friend (NHS Information Centre 2010)



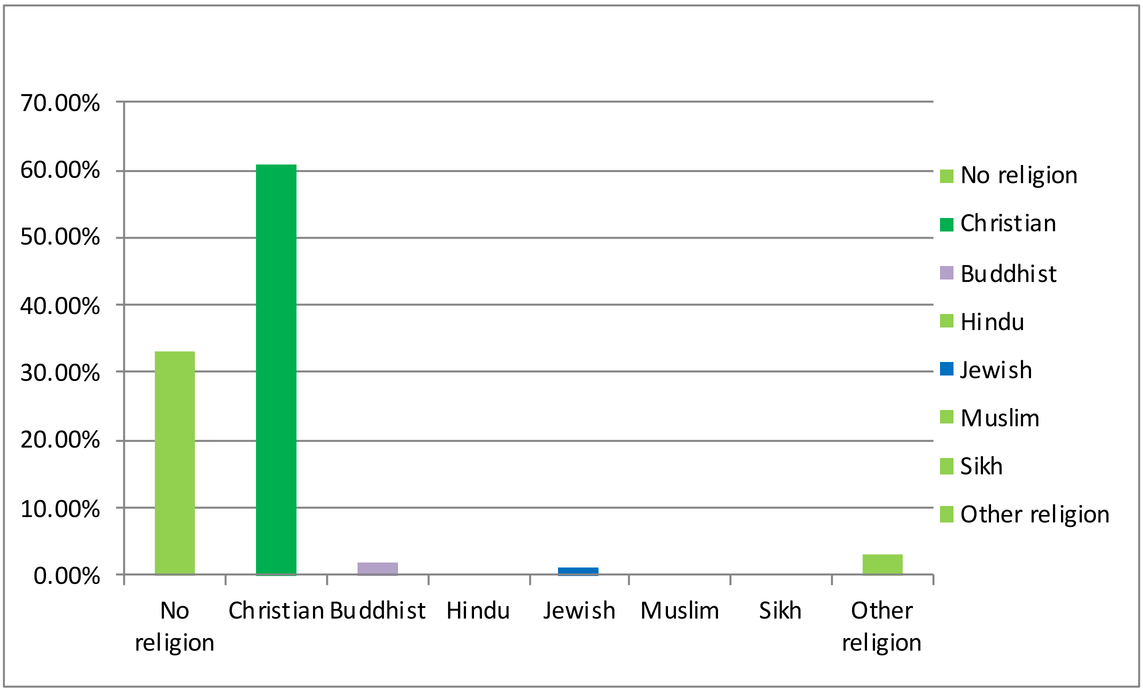
Disability: 33% of respondents reported that they have a disability or a long-term health condition. This does not reflect the results from the 2019 GP Patient Survey which found that carers are more likely to report having a long-term condition, disability or illness than non-carers, with 63% of carers reporting one, compared to 51% of non-carers (NHS England, 2019).

Gender: The majority of respondents, 82%, were female and the remaining 18% were male. 58% of female respondents were carers for their partner or spouse and 37% care for a parent. Among male respondents, 61% cared for a partner or spouse and 22% were carers for a parent. This does not seem to be reflective of the national picture, as the 2011 Census noted that 58% of carers are female and 42% male, although this rises to 60% of carers being female for those caring 50 hours or more a week. 1 in 4 women aged 50 -64 have caring responsibilities, compared to 1 in 6 men. The imbalance reduces amongst older carers where the split is 50:50 aged between 75 – 84, and carers over 85 are more likely to be male (59%) than female (41%) (ONS 2011; NHS Information Centre 2010).

Ethnic Background: 91% of respondents described themselves as 'White English / Scottish / Welsh / Northern Irish / UK. 3% described their identity as Irish, 4% as 'Other' and 1% as Caribbean. Research suggests that a smaller proportion of Black, Asian and minority ethnic populations provides care than the white population, but this is due to the population being younger. Analysis suggests that, when age is accounted for, Black, Asian and minority ethnic families are more likely to provide care for loved ones (Carers UK, 2019).

Marriage / Civil Partnership: 74% of respondents were married or in a civil partnership, 22% were not, and 3% preferred not to say. The Office for National Statistics estimates for 2019 reported that marriage or civil partnerships remain the most common marital status, accounting for just over half (50.4%) of the population aged 16 years or over in England and Wales (ONS, 2019).

Religion: 61% of respondents identified as Christian, 33% said they had no religion or belief, 3% as 'Other religion and 1% Jewish. According to the last census (ONS, 2011), 59.5% of people described themselves as Christian, 25.7% as having no religion, Islam 4.4%, Hinduism 1.3%, Sikhism 0.7%, and Judaism, Buddhism and other religions all as 0.4%. The British Social Attitudes Survey in 2019 (Kelley, 2019) describes a further decline in religion, with 52% saying they are non-religious and only 38% as Christian.



Sexual Orientation: 92% of respondents described themselves as heterosexual, 1% as lesbian, 1% as bisexual, 3% 'preferred not to say', and 3% said they would describe their sexual orientation in a different way to the descriptions given above. The proportion of the UK population aged 16 years and over identifying as heterosexual decreased from 95.3% in 2014 to 94.6% in 2018. The proportion identifying as lesbian, gay or bisexual increased from 1.6% in 2014 to 2.2% in 2018 (ONS, 2018). There isn't an accurate figure for how large the trans community is and the best current estimate is around 1.1% of the population (Stonewall, 2020). There are no clear statistics on the numbers of lesbian, gay, bisexual, intersex, queer or trans carers.

Community Background (For Northern Ireland only): 35 carers answered this question, although only 30 live in Northern Ireland. Of those who answered, 54% said they were from a Protestant background, 31% from a Catholic background and 14% preferred not to say. The 2011 Census found that 48% of the population described themselves as Protestant or brought up as Protestant, and 45% as Catholic or brought up Catholic, with 7% saying they belonged to another religion or none (ONS, 2011)

Appendix B

Steering Group: Terms of Reference

Name of Group

Tide Connection and Information Project Steering Group

Timescale

October 2020 - March 2021

Delivery Model

A co-production model was used. This approach is based on the principles of accessibility, experts by lived experience, collaboration and shared goals, and impact focused.

Purpose

To develop a resource for carers on an issue that's important to them

Role

1. Agree an area to explore that is important to carers of people with dementia
2. Individual evaluation input
3. Plan for a specific information resource on this area of specific interest for carers
4. Participate in relevant training
5. Research area (desk, quantitative and qualitative)
6. Product completion and dissemination (accessibility to be considered)

Membership

Tide carers (up to 8 individuals). Fiona McMahon – tide Carer Development Lead Northern Ireland as secretariat. Individuals can be invited onto the Steering Group or to present to the group as required.

Payment and Accountability

Payment will be £75 (3hrs) and £150 (6hrs). The Steering Group will be accountable, along with tide, to coproduce the project. This means sharing lived experiences of caring for someone with dementia to inform the project and keep it relevant.

Required Commitment

Steering Group members will be required to sign up to a minimum level of commitment. (However, tide acknowledges that carer's lives can be unpredictable and time commitments may change. We are flexible and can manage different levels of commitment when required.)

We require, initially, contribution to up to 6 meetings with preparation and follow-up (up to 3 hours) – a total of 18 hours between 23rd November 2020 and 31st March 2021.

Information Sharing Methods

Information will be emailed, and meetings conducted on Zoom. There will be adjustment made to include Steering Group members by phone and, potentially, one-to-one meetings where possible.

Impact Evaluation

Steering Group members will be required to participate in measuring the impact of the project.

For further information please contact:

Fiona McMahon: tide Carer Involvement Lead Northern Ireland

07841 457596

Fiona@tide.uk.net

Appendix C

Online Survey

Crowded Isolation and Loneliness: the experiences of present and former carers of people with dementia

Caring for someone with dementia can be a lonely and isolating experience whilst at the same time your life feels crowded with the responsibility. You are dealing with a lot of different people, systems and reactions, trying to manage so many things and not knowing if you're doing it right.

Carers of someone with dementia have described experiencing; a **crowded** mind with all the responsibility; daily life filled with caring routines with the prospect of an **isolated** future; alienation as your social life and independence disappear: your home crowded with strangers who are home carers (not there for you) or **isolated** in the house caring for someone; a sense of **loneliness** as person you care for isn't in your home or, if they are at home, they are they 'no longer there' as the person you knew.

All this whilst, feeling a rollercoaster of emotions for the person you care for and for yourself. Ultimately, it can feel that really, you're on your own.

Some definitions may put all this in context:

Loneliness is a normal human emotion. Loneliness is a subjective feeling about the gap between a person's desired levels of social contact and their actual level of social contact. It refers to the perceived quality of the person's relationships. But chronic loneliness – when people always or often feel this way – can be very damaging, and it affects one in 20 people in Northern Ireland. Loneliness is often linked to social isolation, but it is not the same thing.

Social isolation is objective. It describes the quantity of social connections and relationships that someone has – such as whether someone has met a friend in the last week. Loneliness on the other hand is deeply personal. People can be isolated (alone) but not lonely. People can be surrounded by other people, yet still feel lonely.

So, all of this is why we want to open up a conversation. We will be using the responses of this survey to inform resources detailing carers experiences. Your answers will be completely anonymous so you can be as open and honest as you feel comfortable with. We might also use some of your answers in our future work on the experience of carers of people with dementia. Again, this will be completely anonymous, and any identifiable characteristics will be left out. You can participate when you're currently caring for someone, or after your caring role has ended.

There are 8 questions; you don't have to answer them all to participate.

1. Have you ever felt crowded isolation or loneliness your caring role? If so, could you share a bit more about this?
2. Were there any particular moments or events that triggered these feelings?
3. Have you shared these feelings with anyone else? How did you feel afterwards?
4. How would you describe yourself and your life before you became a carer? Work, family, friends? Did you feel isolated or lonely then?
5. What would you like to have known or what advice would you give to yourself at the start of your caring journey?
6. What do you think, but never feel able to say out loud in relation to your experience of crowded isolation and loneliness in your caring role?
7. How have your experiences of crowded isolation and loneliness changed over your caring journey?

8. Do you get any support in your caring role? If you do, where does if come from and what would improve it? (This question is for all different types of present or former caring roles. For example: the support may be practical i.e.: home carers / residential care / community organisations services or the support could be emotional from family, community networks or counsellors)

Would you like to know more about what tide will be doing with the information you have given us? If so, please give us your email.

Would you be willing to be interviewed by another carer about your experiences of crowded isolation and loneliness? If so, please give us your email.

Appendix D

Consent Form

☐ Please click the box to indicate that you have read the information about the project contained in the background document sent to you together with this consent form.

Participation in this telephone or Zoom interview means you provide us with permission to use the data we collect in the interview in tide Crowded Isolation and Loneliness information / reports. Your responses will be combined with those of other participants during the analysis of the responses. Information about individuals or any personal data will not be used. Your participation in this interview is voluntary. After signing this form, you can withdraw from the interview at any time, and you will not be questioned about why you no longer wish to take part.

Consent to participate in the Crowded Isolation and Loneliness telephone or Zoom interview.

You will be participating in a telephone or Zoom interview. We will record Zoom and some phone interviews to capture what is being said to enable us to make transcripts of some of your comments.

☐ I have read and understand the information about the interview that I will be participating in

☐ I understand that taking part in the study may include being audio recorded

☐ I understand that any of my personal details, such as my name, will not be revealed to anyone outside of tide – together in dementia everyday

☐ I understand that my words may be quoted in publications, reports and other outputs but my name or my organisation will not be used

☐ I understand I can withdraw from the interview at any time, and I will not be asked any questions about why I no longer wish to take part

☐ I agree to participate in the interview

Please feel free to contact: fiona@tide.uk.net with any questions.

Please return this form to Fiona directly or to the carer conducting your interview.

Please type your name and date below:

Name:

Date:

Appendix E

Interview Questions

Q3. At any point, were you asked if you wanted to care for someone?	• Was the transition slow, so that you were a carer before you realised? • How would you have responded to this request at the start of your caring journey? • How would you respond now?
Q4. How has your working life been impacted?	• Are you / were you working? • How do colleagues react to you now? Do they keep in touch?
Q5. How have your friendships been impacted?	• Do you feel part of your friend's world? • Do they understand?
Q6. How have your family relationships / dynamics been impacted?	• What would you like your family to know? • What would you like your family not to know?
Q7. Do you feel like you can make plans for your future?	• Do you believe you have a future to look forward to? • Do you feel guilty about it?
Q8. What is it that crowds your life as a carer?	• What occupies your thoughts? • Who / what takes up your time?
Q9. What is it that makes you feel isolated as a carer?	• What have you missed out on? • What can't you do?
Q10. When do you feel most alone?	• Specific time or place, person or memory?

Q11. What could your family and friends do to help you feel less isolated and alone?	
Q12. What could health and social care service providers to help you feel less isolated and alone?	
Would you be interested in being involved in publicity, as part of the campaign for raising awareness of carer's experiences? This might involve telling your story. You would be supported in doing this if you wanted to.	Was there a particular reason a carer said no or yes to this question? If they said yes, what support was the carer looking for?
Note to Interviewer: Please note any emerging themes	

Appendix F

Support Information

If you feel you would like some support, the following information is available online regionally and locally:

Department of Health: The Department of Health provides services in your own area to help and support you. This includes your GP and specialist healthcare professionals: https://www.nidirect.gov.uk/articles/mental-health-support

Minding Your Head - Public Health Agency/ Lifeline: The Minding Your Head website https://www.mindingyourhead.info/services provides contact details for services available across the region both regionally and locally.

Tide Resources – National Advice Support Helplines: A list of support agencies available nationally across the UK is available on the tide website: https://www.tide.uk.net/resources/national-advice-support-helplines-uk-england-ni-scotland-wales/

Northern Ireland-wide Services

Action Mental Health
Web: https://www.amh.org.uk/
Phone: 028 9182 8494
Email: comms@amh.org.uk

Lifeline 24-hour
Web: http://www.lifelinehelpline.info/
Phone: 0808 808 8000

Aware NI – Duncairn Gardens, Belfast
Web: http://www.aware-ni.org/
Phone: 028 9035 7820
Email: info@aware-ni.org

Mindwise – Upper Queen Street, Belfast
Web: http://www.mindwisenv.org/
Phone: 028 9024 8006
Email: info@mindwisenv.org

Inspire – Lombard House, Belfast
Web: http://www.inspirewellbeing.org/
Phone: 028 9032 8474
Email: hello@inspirewellbeing.org

New Life Counselling - Ardoyne Road, Belfast
Web: http://newlifecounselling.net/
Phone: 028 9039 1630

Relate NI - Glengall Street, Belfast
Web: http://www.relateni.org/
Phone: 028 9032 3454
Email: office@relateni.org

Wave Trauma Centre - Chichester Park South, Belfast
Web: http://wavetraumacentre.org.uk/
Phone: 028 9077 9922
Email: adminhq@wavetrauma.org

Trust Support Teams

Belfast Trust - Woodstock Lodge Mental Health Resource Centre
Web: https://belfasttrust.hscni.net/about/facilities/specialist-centres/woodstock-lodge/
Phone: 028 9504 2920

Northern Trust – Holywell Hospital, Steeple Road, Antrim
Web: http://www.northerntrust.hscni.net/services/mental-health-services/
Phone: 028 9446 5211

South Eastern Trust – Down, Ards and Lisburn
Web: https://setrust.hscni.net/service/mental-health-assessment-centres/

Southern Trust – Lurgan Road, Portadown
Web: https://southerntrust.hscni.net/service/mental-health-services/

Western Trust – Glenshane Road, Londonderry
Web: https://westerntrust.hscni.net/services/mental-health-services/

Community and Voluntary Sector Services

Aisling Centre
Web: http://www.theaislingcentre.com/

An Munia Tober – Supporting Traveller Community
Facebook: https://www.facebook.com/An-Munia-Tober-190834687606953/

CLEAR Project
Web: http://www.clearproject.co.uk/

Community and Family Counselling (Holywood Family Trust)
Web: http://www.holywoodft.co.uk/

Community Health and Development Network

Web: https://www.cdhn.org/

East Belfast Community Counselling

Web: http://www.eastbelfastcounselling.org/

Jigsaw Community Counselling Centre

Web: http://jigsawccc.co.uk/index.html

Phone: 028 09543 8166

Mind Yourself

Email: mindyourself@tiscali.co.uk

Niamh Louise Foundation

Web: http://www.niamhlouisefoundation.com/

North Down Community Network

Web: http://ndcn.co.uk/

Appendix G

Recommendations from Previous Reports

Alzheimer's Society (2020) The Fog of Support: An inquiry into the provision of respite care and carers assessments for people affected by dementia.

https://www.alzheimers.org.uk/sites/default/files/2020-09/as_new_the-fog-of-support_carers-report_final-compressed.pdf

Policies and Planning:

- Recognition of carers as a specific group to receive targeted advice and support which should include the offer of psychological support to carers.
- Carers' assessments should be provided at least annually by people trained to Tier 2 of the NHS-backed Dementia Training Standards Framework.
- Councils must be proactive in offering carers assessments once carers are identified and should contact newly identified carers within 4 weeks.
- Dementia should be a searchable category as part of recording systems and councils should ensure records for carers are collected individually.
- Current and former carers, as well as people living with dementia, should be actively consulted as part of any strategy development or key commissioning decisions.

In Partnership: There are some rarer forms of dementia, or smaller population groups affected, who might require specialist support.

- To ensure these people are effectively served, neighbouring authorities or clinical commissioning groups should explore how they can work together, taking account of current and projected future needs.

Organisational Culture:

- Carers' assessments should take a strengths-based approach, focusing on the positive aspects of carers' practice, while also acknowledging the areas in which they might need extra support.
- Assessments should recognise the specific needs of each carer and should be carried out by staff who are skilled in active listening.
- A regular review of the language used in policy and practice should be carried out as the choice of language can have powerful implications for carers, particularly in relation to feelings of guilt.

Practical:

- Provide carers assessments in person where possible and preferred by the individual.
- Encourage and promote peer support groups for carers of people living with dementia.
- Provide a straightforward method of booking overnight care in advance.

Campaign to End Loneliness (2020) Loneliness in Northern Ireland: A Call to Action

https://www.campaigntoendloneliness.org/wp-content/uploads/Loneliness-in-Northern-Ireland-A-Call-to-action.pdf

Recommendations for Next Steps:

1. **A bespoke and fully resourced Loneliness Strategy:** A cross-departmental Northern Ireland strategy for loneliness across all ages, embedded in the programme for government with committed resources and a clear timeframe for development and delivery.
2. **Committee inquiry:** An ad hoc committee, comprising members from each of the standing committees should be established with comprehensive terms of reference to gather evidence and make recommendations to the NI Executive.
3. **Deliver COVID-19 response to loneliness this winter:** supporting communities and service providers and tackling digital inequalities which can exacerbate loneliness.

What a NI loneliness strategy should commit to:

- **Sustainable funding** – Establish a Loneliness and Social Isolation Fund to stimulate innovation and scale up promising approaches to tackling loneliness. Embed a loneliness criterion to existing sources of funding at local, council and regional levels and ensure proactive commissioning of effective interventions, aligned across interagency, cross-sectoral partnership approaches.
- **Lead a public awareness campaign on loneliness** – to raise awareness about loneliness across Northern Ireland and reduce stigma.
- **Develop specific loneliness measures responsive to children and young people** – for example, through the curriculum in schools and youth service provision and include a range of measures to support children and young people at particular risk of loneliness.

- **Support and develop infrastructure to tackle loneliness and increase social connections** – Tackling loneliness should also be prioritised within transport, housing, community planning, community safety, built environment, planning and community spaces. The strategy should enable connections through arts, culture and heritage, sport and physical activity and volunteering.
- **Promote and support opportunities for people to connect** – A comprehensive regional mapping exercise of existing loneliness responses which identifies evidence of best practice, areas for improvement, gaps and duplication in provision. A coordinated rollout of active connector services which reach, understand and support people experiencing loneliness should be informed by the mapping.

How to deliver a successful loneliness strategy for Northern Ireland:

Principles of a future loneliness strategy:

- **Leadership and accountability** – appoint a NI Executive minister and senior responsible owner with lead responsibility for loneliness.
- **Tackling loneliness is everybody's business** – the NI Executive should act as a catalyst to support a whole society response.
- **Co-design and active partnership** – Government should involve experts by experience alongside cross-sectoral stakeholders at all stages of strategy design and development.
- **Scale approaches, prevention and supporting most lonely** - Amplify evidence-based good practice and support services and approaches which are targeted to tackle chronic loneliness and prevention.
- **Embed strategy within a rights and equality framework**.

Structural mechanisms in a loneliness strategy:

- A cross-departmental **loneliness indicator** in the next PfG
- Establish **loneliness champions** across departments and non-departmental public bodies. Consider a regional interim Loneliness Champion.
- A cross-sector **Loneliness Implementation Group** should be established.
- Delivered by **co-ordinated action** across government, statutory bodies, voluntary and community sector and business.
- Produce an **annual report** and develop loneliness impact assessment process.
- **Invest in research** to address evidence gaps.

Carers UK (2015) Alone & Caring: Isolation, Loneliness & the Impact of Caring on Relationships

Alone and caring – Carers UK

1. A stronger rights base in the workplace that government should improve and support with policy and legislation, including a statutory right to 5-10 days of paid care leave and an urgent debate on longer-term leave from work to care
2. Employers should foster a workplace culture where caring roles are supported with carer-friendly policies
3. A radical improvement in the financial support available to carers and their families to prevent poverty and hardship
4. Sufficient and sustainable funding of care and support services to meet the needs of carers and the people they care for
5. A clear duty on duty on NHS bodies to identify carers and promote their health and well-being (England only)
6. Support for national and local advice services that provide carers with essential emotional and practical support
7. Flexibility for local government to foster support networks through housing, planning and welfare policy and to ensure carers are able to remain close to those networks
8. Understanding of the strain that caring can place on relationships and strategies in place to address this. This should include access to counselling services and support for carers

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Carers UK (2021) Breaks or Breakdown: Carers Week 2021 Report

carers-week-2021-research-report.pdf (carersweek.org)

- Increased funding of and access to breaks and replacement care
- Increased government funding for social care
- More help with contingency planning in case carers are unable to provide care
- Clearer/more specific guidance from the government for unpaid carers
- End carers’ financial hardship and ensure a rise in the amount of Carer’s Allowance
- Ensure a supportive healthcare system
- Ensure carer-friendly employment, along with entitlement to paid care leave