

# **Grief takes many forms:**

Supporting older people through loss and bereavement

A Time to Shine Report July 2020





## **About Time to Shine**

Led by Leeds Older People's Forum, Time to Shine is one of fourteen areas which form Ageing Better; an ambitious, large scale programme funded and developed by The National Lottery Community Fund. Ageing Better aims to improve the lives of people aged 50 and over by reducing social isolation and loneliness.

## Introduction

"I have family but I still feel lonely inside, it is hard to describe, I feel very empty...I miss the one person who matters most, they are not there, I can't get away from that." (Participant)

The majority of Time to Shine projects have, to a greater or lesser degree, supported older people through loss and bereavement. Time to Shine funded one project to focus specifically on bereavement; a video project called Life, Loss, Learning and Legacy, led by Lippy People. A small number of projects, such as Carers' Connections, led by Carers Leeds, or Shared Tables, led by Cross Gates and District Good Neighbours' Scheme, are open to all but are particularly appreciated by people who are facing loss or bereavement and offer opportunities for peer support. In many other Time to Shine projects individuals have been supported in their bereavement by kind, caring staff and volunteers as part of their project's person-centred, compassionate and flexible way of working.

At Time to Shine, we learnt that providing a variety of approaches gives people a choice in how and when to connect with others who have also experienced bereavement. As outlined above, this could be a mixture of bereavement-specific and bereavement-friendly projects, formal and informal interventions, group and one-to-one support. Staff and volunteers need to be trained and supported to choose the right words to help people process their thoughts and feelings relating to bereavement, and to signpost to suitable sources of bereavement support. Cultural and religious customs need to be adhered to and understood, for example in relation to mourning periods.

The purpose of this report is to share quotes from people who are bereaved to start conversations about bereavement, grief and loss. This learning identifies some of the complexities surrounding bereavement and highlights the importance of talking, which in turn may help front-line staff and volunteers to feel more confident in their conversations about death and dying.



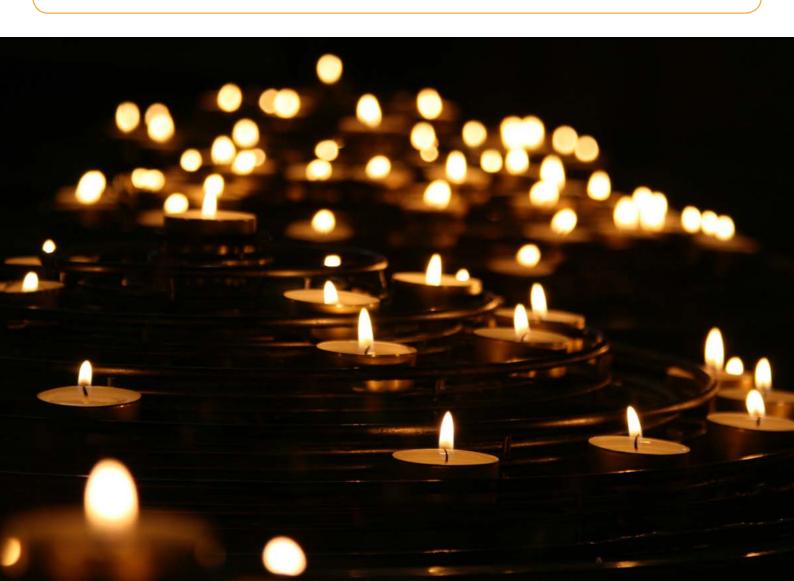
### **Evidence**

Time to Shine has funded over 100 projects (2015-2020). Delivery partners collect case studies, quotes, insight and learning on a regular basis. Research is integral to the Time to Shine programme and the local evaluation team, based at the University of Sheffield, has carried out numerous interviews and focus groups with participants, volunteers, staff and stakeholders. This evidence has informed the report.

### Insight from a Time to Shine delivery partner

Sage is an LGBT project funded by Time to Shine. The project worker noted how other participants can self-organise and be a huge source of support to their peers, particularly when family members are absent:

"I expected that other participants, once notified [of his terminal illness], would make some limited telephone contact with the sick participant. Reality hugely differed from expectations – it was overwhelmingly better. Sage members supported the participant during his time in hospital. Participants arranged a bedside rota during his last days of life and prevented him from dying alone. What was especially remarkable was that the experience also brought living participants together in interdependent and peer-supportive, self-led ways: after his death they met up to discuss their feelings and organised a memorial for the deceased."



## **Learning from Time to Shine projects**

It is, perhaps, unrealistic for programmes such as Time to Shine to aim for completely alleviating loneliness (particularly if this is borne from bereavement), and the best that can be achieved is providing support, a purpose, and something that may occupy someone, or that they can enjoy. Time to Shine has gathered together some of the specific learning points shared by participants, volunteers and staff as they talk about bereavement and loss.

## Everyone has a different experience of bereavement and feels grief in a way that is unique to them:

"Anniversaries were difficult for R to cope with. She would go to bed for 2-3 days during difficult times, and neglect her wellbeing. I was able make a plan with her for formal and informal support on the anniversary of her son's death, and Christmas." (Staff member, Supporting Wellbeing)

### Bereavement can be devastating for those left behind:

"I always had people around me. When I lost my husband I felt cut in half" (Participant)

# The strength of feeling that occurs following bereavement is not always understood by friends and family:

"My friends don't see me so much anymore, as they probably don't know how to take me, I can be in the kitchen and start crying [referring to her bereavement]" (Participant)

## It takes time to get to know a person and gain their trust. This is an important step to helping them open up about their experience:

"Participants had become isolated as a result of bereavement, loss of friends resulting from retirement and from moving house. They spoke of feeling separate, alone, empty and isolated. This created feelings of sadness, unhappiness, nervousness, moodiness and a lack of confidence. Weekends, evenings, dark winter nights, coming back to an empty house and simple things going wrong were dark moments." (Local evaluator)

## Someone who is bereaved may want to talk about how they are feeling, but may not feel able to start that conversation:

"It's important for someone else to explicitly say "How are you feeling now about her/ his death?", however difficult it might feel to do this. If they then don't want to talk about it, that's OK" (Staff member, Time to Shine)

# The need to link with others who have also experienced bereavement is important: "I've got very friendly with one of the other volunteers; we both lost our husbands around the same time" (Cara volunteer)

Bereavement may be one of many problems that a person is dealing with and it's important to signpost to (or provide) practical as well as emotional support:

"A person who is widowed, their main problem may be dealing with legal affairs; these problems need to be dealt with before you can get them to take part in something" (Focus group member)

### People may prefer informal instead of formal bereavement support:

"I worked closely with the suicide bereavement service (who had provided Y with 4 home visits) in order to identify that he wasn't ready for 'formal' bereavement support, but required ad hoc/out of hours support. We created a support list of emergency contacts which Y states he uses" (Staff member, Supporting Wellbeing)

Some people need less support than others to reconnect with their community after bereavement:

"P was told about a number of social opportunities in her local area in her first session and quickly took up a number of these opportunities" (Staff member, Carers' Connections)

For older LGBT people, there is often an extra societal barrier to be worked through if people are 'in the closet'. They may be are reluctant to approach mainstream services as they don't always feel safe and fear the judgement and attitudes of others:

"It needs to be a safe place to be, we need to be ourselves" (Sage focus group member)

For older people with learning disabilities access to appropriate information may be limited:

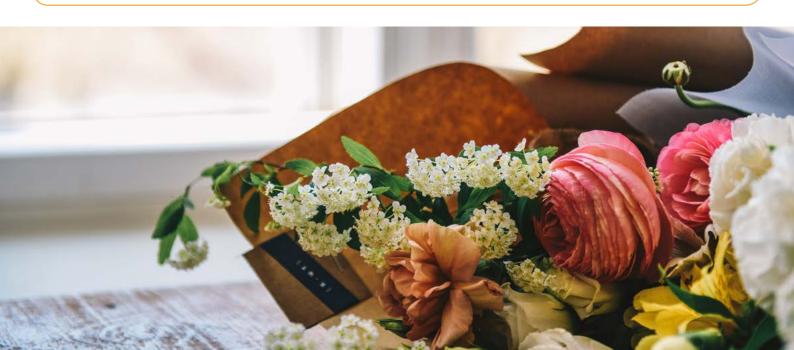
"People with learning disabilities are living longer and need accessible, easy-read information about funerals, will writing etc. Society is not yet geared up for this but we need to start now." (Staff member, Bee Together)

Training and support is essential for staff and volunteers when working with people who are struggling with the loss of someone close to them:

"I particularly benefited from gaining a better understanding of how to listen to someone when they are talking about bereavement. Now have a better understanding of how and why people deal with bereavement differently." (Time to Shine training course attendee)

#### It's important to work with people at their own pace:

"Several participants also spoke of the emotional and physical exhaustion experienced in bereavement and its aftermath and the need for some quiet time. This suggests that some people may be more receptive to Time to Shine activities later rather than sooner." (Local evaluator)





# Outcomes for older men involved in the Life, Loss, Learning and Legacy project

Time to Shine funded Lippy People to deliver an element of their 'Life, Loss, Learning and Legacy' project to focus on older, bereaved men in Leeds. The project used video storytelling as a means of coaching ten groups of older male volunteers across Leeds to tell and share their overlooked, unheard stories of lived experience. Participants were encouraged to share their feelings and the group was a safe space to be sad, angry or confused.

#### **Evidenced outcomes include:**

- Reduced social isolation of older men
- Increased confidence and self-belief
- Transformational changes in attitude and understanding around life and death
- New ways to manage, discuss and process loss and bereavement
- New meaningful friendships
- First time volunteering for many of the men, giving a sense of purpose and reward
- Positive impacts on family relationships as a result of the project

A separate Time to Shine learning insight, written in partnership with Lippy People, complements this report. The video stories are on YouTube and links to both are included on page 8 of this report.

# Case study from Don't Call Me Old at Armley Helping Hands

J lived with his mother all his life and she had cared for his every need for over 60 years. J's mother had started to show signs of dementia and as the months went on this started to get more pronounced. This had a deep effect on him and he was extremely upset and couldn't understand what was happening to his mother.

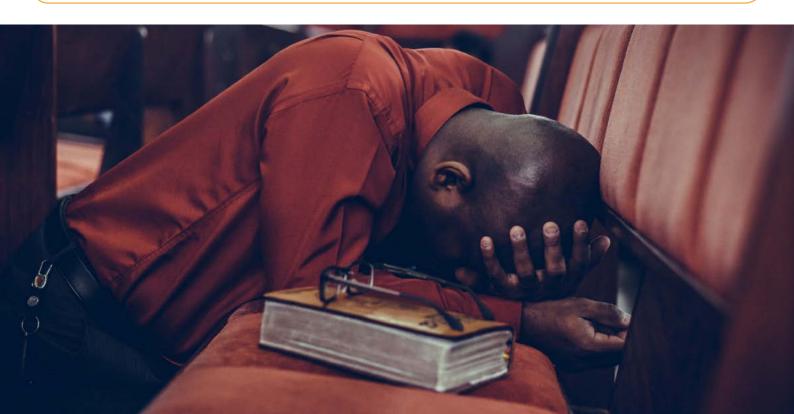
J and his mother had attended activities together at Armley Helping Hands for many years and the project worker often mentioned the Don't Call Me Old project. He seemed interested but said he couldn't because he needed someone to sit with his mother.

After a few months, his mother moved to a care home for 24 hour support. J took the move badly and was upset. He visited her every day and it became the norm for him to spend the full day there looking after her and feeding her. As his mother's health deteriorated so did his. J was withdrawing more and more into a shell he had built up around himself. Although he had become a regular at the men's group at Don't Call Me Old he didn't seem to participate much in any of the activities. This continued for 8 months until sadly his mother passed away at the home.

Her death had a massive effect on him as he had visited as usual but left at 7pm and she died a couple of hours later. He blamed himself for not being there.

At the funeral the Don't Call Me Old project worker stood with J and they said a small prayer when the other mourners and family had moved away. After the funeral he went back to the wake and stayed with J until it had finished, taking him home afterwards to make sure he was ok.

At the men's group one of the members mentioned a project we were running with Leeds museums. J said he was interested and would come along. This led on to J coming to other groups and asking if he could help out at the foodbank. These social connections have really helped his mental health although he still has days when he feels alone and upset.



## **Insight from a Time to Shine delivery partner**

The Street Links project worker at Richmond Hill Elderly Action (RHEA) explains how the input and endorsement from a trusted member of the community helped them to make connections with people who would benefit most from their support:

"We attended the Working Men's Club on a Sunday where we knew around 150 older people from all areas of Richmond Hill attended. We felt that by finding already well established meeting places in the community we would be able to successfully target older people, raising awareness of the Street Links Project and RHEA.

We found a significant proportion of those attending the Working Men's Club were bereaved men. We built a partnership with the stewardess who sold tickets for the Bridlington trip [we'd arranged] and encouraged participation, particularly from the harder to reach older people. The stewardess knew all the really important information about her customers, who was poorly, who was in hospital, who had been bereaved, who had passed away."

#### **Additional Resources from Time to Shine**

- Trigger points: How might older people fall into social isolation and loneliness? How can we help them to re-connect? A Time to Shine Report and Toolkit, July 2020
- <u>Life, Loss, Learning and Legacy: Learning from men's experiences of bereavement</u> A
  Time to Shine learning insight written in partnership with Lippy People, July 2020
- To watch all 15 video stories created by Lippy People as part of the Life, Loss, Learning and Legacy project at Time to Shine go to Lippy People's YouTube channel on <a href="https://bit.ly/4Lsvideos">https://bit.ly/4Lsvideos</a>
- All Time to Shine reports are available on the <u>learning section of the Time to Shine website</u>

#### Additional resources and services from other organisations in Leeds

- <u>Leeds Bereavement Forum</u>
- Cruse Bereavement Care, Leeds
- Age UK, coping with bereavement
- The West Yorkshire and Harrogate Health and Care Partnership Grief and Loss Support Service