Accessible Bereavement Resource Pack

- An information pack on the impact of bereavement on older people and stroke survivors;
- A resource for those supporting people who have communication difficulties (such as aphasia) who are bereaved.
This resource pack has been produced by the Beyond Words project, a joint venture between Cruse Bereavement Care and Stroke Association in support of the needs of bereaved older people and stroke survivors. The Beyond Words project is funded by the Big Lottery Fund.

The aim of this resource pack is:

• To provide information on the impact of bereavement on older people and stroke survivors;

• To provide a resource for those supporting people who have communication difficulties (such as aphasia) who are bereaved.

This resource pack is designed to be used by a wide range of people, for example, GPs, health and social care staff, volunteers, carers and family members.
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Introduction

In Northern Ireland there are over 15,000 deaths each year, with 82% of these deaths in the over 60 age group. Approximately 4,000 people in Northern Ireland have a stroke each year, with stroke being the third most common cause of death. While a stroke can strike at any age, a large percentage of people who have a stroke are over 60. There are currently around 34,000 stroke survivors in Northern Ireland, with approximately 10,000 living with the communication disability known as aphasia. Aphasia can affect a person’s ability to speak, read, write and understand.

The death of someone very close, at any age, can be a lonely and bewildering experience. The loss of a partner, brother, sister, parent or child is a major life change. It may affect the lifestyle, attitudes and personality of the person who is bereaved and their relationship with those around them. Intense feelings, confused thoughts and strong physical reactions are common to bereaved people of all ages. Many people find that the invaluable support and comfort which is often available in the early days of bereavement may no longer be there when the full impact of loss sets in.

Everyone experiences grief differently; there is no ‘normal’ or ‘right’ way to grieve. How a person reacts will be influenced by many different things, including:

• age;
• personality;
• cultural background;
• religious beliefs;
• previous experiences of bereavement;
• individual circumstances;
• coping mechanisms;
• support from others.

For older people, bereavement can be particularly difficult. Losing a close family member or friend can mean that there is no
one who shares childhood memories, ways of life that are gone or even family jokes. When a close relationship ends through bereavement, life can change significantly. On a practical level, there may be many tasks and needs which are now left unattended. Filling these roles, alone and unsupported, can be overwhelming. For example, if one partner has always dealt with all the couple’s financial matters or their domestic chores, the remaining partner may find it difficult to manage. An older person who has been bereaved may find that they are alone for the first time.

Grief through bereavement can also occur when an older person feels least able to deal with the life-changing impacts that the death of a lifelong partner, friend, brother, sister or child can have. A death can bring back the memories of a series of losses experienced over a long lifetime, such as the deaths of parents and friends. It can come at a time when previously reliable support systems have become weakened or disappeared.

Grief for older people can mean an increased likelihood of having feelings of sadness, loneliness, and depression. Older people may tend to ruminate over their loss, especially if most of their family and friends have died.

Older people and stroke survivors may feel others are treating them differently, e.g. support workers and carers may seem to be over protective in trying to shield them from the harsh realities of life, fearing that they may not be able to cope. Those who are living at home or in other care settings may also experience on-going changes that are beyond their control which give rise to anxiety, for example, staff turnover and changes in living arrangements.

If the person has a limited number of close relationships and social supports, the impact of these losses may be more magnified than would otherwise be the case. If the person who has died is the primary care giver, then the loss can be experienced in many ways. As a result of the death, the stroke survivor or older person may not only experience the loss of someone they care very much about, but potentially also experience major changes in their daily routine, social life, living arrangements and financial circumstances. The loss may also create feelings of insecurity about their day-to-day living, care and future.

Some people who have had a stroke have complex communication needs (aphasia). They may be unable to use speech to fully meet their daily communication needs. They may rely, to varying degrees, on a range of communication methods such as writing, drawing, gesture and facial expression. They may also rely on other communication supports, for example, the use of pictures, communication book, lightwriter and specialist iPads. A person with aphasia may have difficulty expressing their emotions, asking questions and conveying information about grief and loss.

Additionally, stroke survivors can be dealing with depression as a result of their stroke and loss of what they may have been able to do previously. Often people complain more about the physical rather than the emotional signs and symptoms of depression so that the problem of depression often goes unrecognised. This can have a big impact on the stroke survivor’s ability to deal with bereavement.
Part 2:

Introduction

This section is intended to provide guidance and techniques to support individuals with aphasia and other communication difficulties.

Good communication guidelines

It is important to consider ways which make interactions as supportive as possible for the person with aphasia. More effective communication may be attained by:

- Adapting the environment
- Good communication practices
- Communication props and strategies

Adapting the environment

Prepare the environment by setting aside adequate time for the interaction so that there are no time pressures. It is also important to consider the time of day that the interaction is taking place. Some people with communication difficulties find their concentration and memory is better or they are less tired in the morning and this enables them to communicate better at that time, while others find they can communicate better in the later part of the day.

It is important to face the person with aphasia rather than sit alongside them. This means that they will be able to pick up any gesture, or facial expression. Check that they are comfortable and happy to interact and that any hearing aids or glasses are being worn. Make sure you have good eye contact. Check that the lighting is adequate and that the temperature of the room is comfortable. Try to address any sources of background noise, such as the television or washing machine if working with someone at home. It is best to have an environment free from distractions and interruptions as privacy is important.
Good communication practices

• Gain the person’s attention
Before you begin the conversation ensure the person is tuned in to you. You can do this by, for example, saying their name, gently touching their arm, using an alerter phrase such as, “I want to ask you” or “Let’s talk about…”

• Let the person know you are listening
We all need to know that we are being listened to in a conversation. This can be done by simply nodding, or saying, “Yes” or “Uh huh”. You also need to let the person with aphasia know whether or not you have understood their message. You may need to recap. Using gesture or drawing can significantly help communication. If you gesture or draw as you talk it reduces embarrassment for both of you and encourages the person with aphasia to have a go at communicating. If you get stuck, acknowledge the difficulties, recap where you have got so far, and decide whether you are going to carry on or come back later.

• Slow down
Many of us speak too quickly without being aware of it. Some people with aphasia require more time to process the meaning of sentences. You may need to talk in a relaxed way, slow your speech and repeat key information. Ask the other person if you are speaking at the right speed and volume.

• Keep sentences short and use pausing
People with aphasia often find it hard to take in lots of information at once. Use one short sentence, idea or instruction at a time. Ask closed questions – i.e. those that require a yes/no answer. Allow a long pause to give the person plenty of time to think about their answer and respond. Recap and repeat to make sure you are on the same track.

• Be direct and specific
Use specific words that make the meaning of your sentence as clear as possible.
For example, “When did your partner die?” rather than “When did you lose your partner?”
“Are you feeling sad?” rather than “Are you feeling down?”

• Emphasise key words
When communicating with a person who has aphasia, it is important that you emphasise the key words or message that you want the person to understand. This can also be done by repeating the key word, writing it down and pointing to it. This is very important for the person who has difficulties with understanding.
For example, “Is this your sister in this picture?”

• Avoid abrupt topic changes
Keeping to one topic at a time is less confusing for a person with aphasia. If you need to change the topic it is important to alert the person with aphasia by:
- Using a verbal prompt, “Now let’s talk about.”
- Pausing between topics
- Changing your posture - leaning forward
- Using pictures, when appropriate

• Communication props and strategies
It is important to have the following communication tools to hand: pen and paper; clipboard for the person to lean on if they want to draw or write something; yes/no cards (see example in Part 5); a diary or calendar; and alphabet chart.
Depending on the topic being discussed, it may be useful to have photos, newspapers or magazines to hand. Some people may use a communication book to support their speech. A communication book is a personalised collection of relevant information about the person’s life, often in the form of pictures, which can be pointed at to help support interaction.
## Communicating with people who have aphasia
(when it is hard to speak, read, write or understand)

**Repeat information**
- Get their **attention**

**Keep it simple**
- Reduce background noise

**Stay positive**
- Allow **time** to understand and respond
- Check **yes/no** response
- If one thing does not work, try something **different**

### Do...
- Repeat information
- Keep it simple
- Stay positive

<table>
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**Accessible Bereavement Resource Pack**
And finally...

Support given to people with aphasia who are affected by bereavement is not solely reliant on effective communication techniques but also on the personal qualities of the person providing support. Three such qualities are:

- **Empathy**: the ability to experience another person’s world as if it were one’s own;
- **Acceptance**: accepting and respecting the person irrespective of his/her behaviour, thoughts or feelings etc;
- **Genuineness**: what we do or say matching what we think and feel.

These qualities help establish a relationship of trust whereby those bereaved feel safe to reveal their innermost thoughts.

Following good communication guidelines such as, making changes to the environment, using good communication practices and using specific communication props and strategies may contribute to more effective communication. As a result, the support offered to individuals with aphasia and other communication difficulties is enhanced.

Ten top tips for talking with people with aphasia

1. Use pen and paper
2. Say one thing at a time
3. Don’t rush - slow down, be patient
4. Don’t pretend you understand
5. Draw diagrams or pictures
6. Write down key words
7. Relax - be natural
8. Recap - check you both understand
9. Ask what helps
10. Reduce background noise
Introduction
The following information is intended as useful background reading on bereavement for those working with a bereaved person. While the information is generic to anyone who has been bereaved, it is of course equally relevant to those who have communication difficulties such as aphasia. All of the information is reflected in the accessible information in Part 4.

Responses to bereavement
Bereavement affects people in different ways – there is no ‘right’ or ‘normal’ way to grieve. Everyone’s experience will be individual to them. It is common for people to experience some or all of the following reactions at some stage, which can be frightening and can make the bereaved person feel as if they are losing control or ‘going mad’. However, these are all ‘normal’ and should lessen over time.

Feelings
Feelings following bereavement can be very strong and can include:

- **Fear** – of being left alone; of the same thing happening again;
- **Confusion** – taking in what has happened - that the person has gone;
- **Sadness** – about the death and about other deaths the person has experienced;
- **Longing** – for things that are gone or can’t happen now;
- **Guilt** – for being alive when the other person is dead; for things they may have said or done or not said and done in relation to the dead person;
- **Shame** – for being seen to be helpless, emotional and needing others;
- **Anger** – about what has happened; about having to deal with the aftermath;
- **Numbness** – the death may seem unreal, like a dream;
• Emptiness and hopelessness about the future – feeling that life is not worth living. Some people may even feel they want to end their own lives;
• Relief – sometimes a death can feel like a relief for the bereaved person – this may be because their relationship with the deceased person was difficult or because the deceased person suffered a lot before their death;
• Mood swings – a bereaved person can feel that they’re on an emotional rollercoaster.

Thoughts
Bereavement can also affect a person’s thinking processes.
• Memories – constantly thinking about the person who has died and other bereavements;
• Inability to concentrate – feeling jumpy, restless and anxious;
• Difficulty making decisions – often about simple things, because of anxiety;
• Pre-occupation with the events or circumstances of the death – constantly going over the events leading to or circumstances of the death;
• The bereaved person may also have thoughts such as:
  “I will never get over this.”
  “Will I always feel this way?”

Behaviours
Grief can also change a person’s behaviour and may include:
• Crying - more frequently than before or crying in situations that wouldn’t normally be seen as an occasion for tears;
• Withdrawal – from friends, relatives and situations that are a reminder of the person who has died;
• Sleep disturbance – caused by dreams, flashbacks and restlessness;
• Eating less or eating more than usual;
• Drinking alcohol excessively or taking drugs to dull the pain.

Relationships
Relationships with others – e.g. family and friends may be affected. Some people may be able to support one another, but others may struggle. A bereavement can bring people together but it can also create tensions and strains. A bereaved person can feel isolated, despite the presence of family and friends and this can be particularly the case when a person has had a stroke and/or has aphasia.

Encouraging self-help
Communicating about the person who died, dealing with the practicalities of their new situation, and trying to think of the present as well as the past all help a bereaved person get used to the reality of the death and get through times of anguish. As a person does this, they may slowly begin to find a way of living without the person, while still having their thoughts and memories.

It is important for the bereaved person to:
• Have time to grieve and understand that crying is a normal way to release feelings. It is important that people do not keep their emotions bottled up.
• Be able to talk or communicate to other people about the person who has died and not to isolate themselves;
• Eat properly and try to get enough rest (even if they can’t sleep). Turning to drugs and alcohol will only offer temporary relief;
• Try to set routines – this might be to re-establish old routines or set new ones;
• Have space to grieve and a comfortable place to relax;
• Be able to seek help and support if they need it and not feel guilty or weak when they are struggling.

Suggested activities that can help
• Spending time with people who understand;
• Visiting places that hold meaning – for
example the grave of the deceased person;
• Creating a memory box of mementoes or even a memory garden – this can be a helpful focus for a person’s grief;
• Creating a memory book of photos, cards or letters;
• Keeping a journal which can help to process painful feelings that a bereaved person may find hard to share;
• Putting together a calendar that helps the person plan and look forward to upcoming events.

Significant times and triggers
There are some occasions and triggers which are unique to each bereaved individual. When supporting a bereaved person, it is helpful to be sensitive to these. Such occasions and triggers may be birthdays and anniversaries; seasons of the year; weddings and funerals; music; pictures; photos; films; other people’s stories; and even global events. Some people find it helpful to plan in advance what they are going to do on those days.

Good practice guidelines when supporting a bereaved person
As already covered in Part 2 of this publication, it is important when communicating with a bereaved person to have empathy; to be able to accept and respect a bereaved person irrespective of their reactions; and to be genuine.

On the other hand, it is best NOT to:
• use clichés such as: “I understand how you feel”; “You’ll get over it”or “Time heals”.
• use statements that begin with “You should” or “You will.” These statements can be seen as instructions. It’s better to begin your comments with: “Have you thought about. . .” or “You might”
• suggest that “This is behind you now; it’s time to get on with your life.” Sometimes bereaved people can be resistant to moving on with because they feel this means ‘forgetting’ their loved one. In addition, moving on is easier said than done. Grief works at its own pace - how long a person needs to grieve is entirely individual.
• feel like you have to have the right answers and get it right all the time.
Part 4:

Bereavement information in an accessible format

About this section

This section provides information about and strategies for dealing with grief and loss, in an accessible format. It can be used in two ways: as an easy read guide for a person with aphasia or communication difficulty; or as a toolkit to assist communication between a person with aphasia and a person who is working with them in relation to the topic.
What is grief?

Grief is what we may feel after we have lost someone or something.
Grief could be caused by:

Someone dying

A pet dying

A relationship ending
Grief could be caused by:

Not being able to reach a goal you wanted

Not being able to do the things you used to
When someone dies you may have different feelings. You may feel:

Sad

Angry

Empty or hopeless about the future
Afraid

Confused

Guilty

Relieved
You might have thoughts like:

It’s not true?

Why me?

I can’t concentrate

I will never get over this
You may behave differently. You may:

Cry more

Want to spend time on your own

Lose interest in things

Want to drink more alcohol or take drugs
You may behave differently.
You may:

Eat more

Eat less

Sleep more

Sleep less
Your body may be affected - you may:

Get headaches

Feel very tired

Feel sick
Relationships may be different - a death can:

- Bring family and friends together
- Push family and friends apart
- Make a person feel very alone even when they are with other people
It’s ok to have lots of different feelings - to:

Cry

Talk about it if you want

Not talk about it if you don’t want to
You may feel sad on special days:

Anniversaries

Christmas

Birthdays
What helps

Share your feelings with someone you are comfortable with

Give yourself time

Remember it’s ok to go through a hard time
Other things that might help:

Eat properly

Try to get enough rest

Do the things you normally do
Do things that may give you comfort such as:

- Visiting the grave or a place that holds special memories
- Making a book of sympathy cards
- Making a memory book/box about the person
Do things that may give you comfort such as:

Finding a poem, saying or song that helps

Planting something in memory of the person
Remember...

What you decide to do is up to you

You will probably feel better in time

If you don’t feel better, ask for help

Stroke Association and Cruse Bereavement Care can help
Part 5:

General toolkit to aid communication

How to use this section

The following items have been included in order to aid communication in general with a person who has aphasia. These could be used by:

- Asking the person to point to promote communication e.g. clarifying Yes/No by pointing
- Checking that you both have the same understanding of what is being communicated
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Days of the week

Monday
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Th F S

Tuesday
Su M T W
Th F S

Wednesday
Su M T W
Th F S

Thursday
Su M T W
Th F S

Friday
Su M T W
Th F S

Saturday
Su M T W
Th F S

Sunday
Su M T W
Th F S
Months of the year

January
February
March
April
May
June
July
August
September
October
November
December
Map of Ireland
### I feel...

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<th>Depressed</th>
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<td>Happy</td>
<td>Excited</td>
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<td>Tired</td>
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<td>Cold</td>
<td>Hot</td>
<td>Dizzy</td>
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Support available and links to reference material

Support available

Cruse Bereavement Care

Cruse is a national charity that provides advice, information and support to anyone who has been bereaved whenever or however the death occurred. The service is provided by trained, experienced volunteers, and is confidential and free.

Cruse provides face-to-face, telephone, email and website support both post- and pre-bereavement. We have a national helpline, and local services throughout England, Wales and Northern Ireland.

We offer:

• Someone to talk to face-to-face, or on the telephone
• Online support
• Groups – some bereaved people find it helpful to talk to others in similar circumstances
• Information about many aspects of bereavement and other sources of help and support
• Face-to-face, telephone helpline and online support for children and young people.

For help and support and for details of your local Cruse service:

• visit our website at www.cruse.org.uk
• call our Northern Ireland office at 028 9079 2419
• telephone our national helpline on 0844 477 9400
• email us at helpmail@cruse.org.uk
Stroke Association

Stroke Association is the only UK wide charity solely dedicated to combating stroke in people of all ages. Our services directly help people affected by stroke and their families and carers. We raise essential funds and sponsor research into prevention, treatment and better methods of rehabilitation. We also campaign, educate and inform to increase knowledge and understanding of stroke at all levels of society.

In NI we offer:
- Speech and language therapy and communication support programmes
- Information, advice and support services
- Home visiting
- Befriending - all stroke survivors
- Training and education
- Carer and family support

For help and support and for details of your local Stroke service:
- visit our website at www.stroke.org.uk
- call our Northern Ireland office at 028 9050 8020
- telephone our national helpline on 0303 3033 100
- email us at info@stroke.org.uk

References

**Has Someone Died? Cruse Bereavement Care.**
www.crusebereavementcare.org.uk

**Bereavement and Older People, Cruse Bereavement Care.**
www.crusebereavementcare.org.uk

**Coping with Trauma and Loss, Cruse Bereavement Care.**
www.crusebereavementcare.org.uk

**Supporting People with Disabilities Coping with Grief and Loss.**
Scope (Vic) Ltd, Melbourne, Australia.
www.scopevic.org.au

**Bereavement – Support after a Death, Age UK.**
www.ageuk.org.uk

**Bereavement and Stroke.**
Stroke Association
www.stroke.org.uk

**Communication Problems after Stroke.**
Stroke Association
www.stroke.org.uk

Oxford: Speechmark
The ‘Beyond Words’ Project provides:

- Bereavement support for: older people over 60 years of age, people living in sheltered housing and stroke survivors and their carers.
- Information on bereavement services
- Specialist service for stroke survivors with aphasia
- Training in communication and bereavement awareness for Health and Social Care Trust Staff and Students
- Support activities and signposting.

The Health and Social Care Trusts have web pages for their bereavement support services:

- http://www.belfasttrust.hscni.net/services/Bereavement.htm
- http://www.setrust.hscni.net/services/2298.htm
- http://www.southerntrust.hscni.net/services/2397.htm
- http://www.northerntrust.hscni.net/services/1847.htm
- http://www.westerntrust.hscni.net/services/1618.htm

They also have a wide range of practical information and leaflets such as:

- Practical information for when someone close to you dies; www.belfasttrust.hscni.net/pdf/When_Someone_Close_to_You_Dies_Practical_Information.pdf
- Coping with Bereavement (in a selection of languages); www.southerntrust.hscni.net/services/2397.htm
- Information and guidance following the death of a close relative; www.setrust.hscni.net/pdf/SET_Death_of_a_Relative_or_Friend>Aug_13.pdf
- When Someone Dies; www.northerntrust.hscni.net/pdf/When_someone_dies_booklet.pdf
- Belfast Trust 028 9063 3904
- Northern Trust 028 9442 4992
- Southern Trust 028 3861 3861
- South Eastern Trust 028 9055 3282
- Western Trust 028 7143 5171

Other organisations that can help:

- ageNI
- Foundation for the study of infant deaths
- The Miscarriage Association
- Samaritans
- Soldiers, Sailors, Airmen and Families Association
- Support After Murder and Manslaughter (SAMM)
• The Terrence Higgins Trust (AIDS or HIV)
• Survivors of Bereavement by Suicide
• Child Bereavement Charity
• Citizens Advice Bureau (CAB); www.citizensadvice.co.uk
  Central Belfast CAB; 0300 1 233 233
  Or there are local CAB Offices in:
  Antrim, Armagh, Ballymena, Banbridge, Bangor, Belfast,
  Carrickfergus, Coleraine, Cookstown, Craigavon, Derry-Londonderry,
  Downpatrick, Dungannon, Fermanagh, Holywood, Larne, Lisburn, Newry,
  Newtownabbey, Newtownards & Strabane.

• If you need to report the death of someone receiving Social Security benefits, you can do this by contacting The Bereavement Service using a dedicated free phone number; 0800 0852463. www.nidirect.gov.uk/the-bereavement-service

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In Northern Ireland there are over 15,000 deaths each year, with 82% of these deaths in the over 60 age group. Approximately 4,000 people in Northern Ireland have a stroke each year, with stroke being the third most common cause of death. While a stroke can strike at any age, a large percentage of people who have a stroke are over 60. There are currently around 34,000 stroke survivors in Northern Ireland, with approximately 10,000 living with the communication disability known as aphasia. Aphasia can affect a person’s ability to speak, read, write and understand.
Stroke Association is the only UK-wide charity dealing with stroke in people of all ages. It works to prevent strokes and support those affected by stroke through a wide range of services, campaigning, research into prevention, treatment and rehabilitation.

Cruse Bereavement Care is a national charity which offers support, advice and information to children, young people and adults when someone dies and aims to enhance society’s care of bereaved people.