

NHS Greater Glasgow and Clyde Learning Disabilities Service

COVID19 and Bereavement: Supporting People with Learning Disabilities



This leaflet should be used alongside 'When Someone Dies From Coronavirus: a Guide for Family & Carers' which can be downloaded from <https://booksbeyondwords.co.uk/coping-with-coronavirus>

Together, these two resources will help you support the person you care for following the death of someone who has died because of the virus.

It is important to remember that *while this is a new virus, the way we help people with learning disabilities to cope with death remains the same:*

- People with learning disabilities grieve in their own way, just like everybody else
- Withholding information about a death, even if you think it might reduce anxiety, is often not helpful in the longer-term
- Most people with learning disabilities will progress normally through the grief cycle/ process
- We may see a delayed reaction in people with a learning disability - they may appear to cope initially and then may become upset some weeks, months or even years later. This is fairly common, and the person should be allowed to grieve as normal
- A person's communication skills will affect their ability to understand and express how they are feeling. You will need to adapt your communication to help.

What if nothing seems to work or I am worried?

If you feel that someone is not coping very well with the loss of someone, or if their grief seems to go on for a very long time (usually more than 6 months from initial signs of grieving) additional support might be required. It would then be important for you to contact someone to talk about whether additional services from your local Community Learning Disability Team would be useful. You, or the person that you support, can contact their GP or social worker to discuss this.

COVID19 and Bereavement: Tips for Supporting People with Learning Disabilities

Here are some additional tips to help you to support someone who has a learning disability through a bereavement:

Talk

Use words that are easily understood by the person you are supporting. Use words to describe the death in a concrete way e.g. 'they have died' rather than 'they have gone to a better place/ to sleep'.

Talk openly, if you can, about the person who has died. This gives the person the opportunity to understand that loss has happened and that it is OK to talk about it.

Talk about what is happening e.g. the funeral process.

Try to answer questions as concisely as possible. Use the Books Beyond Words booklet 'When someone dies - An easy read leaflet to help to support people with learning disabilities through a bereavement'.

Involve

Involve the person in the process e.g. choosing flowers, choosing what they can wear to the funeral. If you cannot attend the funeral then perhaps have a small service at home.

Try to let the person make their own decisions about what they want to do.

Let the person decide whether they want to keep any particular items to remember the person by.

Reassure

Reassure the person that it is OK to cry and to have a range of feelings (e.g. sadness, anger and fear).

Do not assume that you know how the person will be feeling- we all experience things differently.

Listen rather than try to fix it. They need to work through the process themselves.

Be patient- make time to be available and to listen.

Reassure the person with a learning disability that the person's death was not their fault.

Encourage

Encourage routine activities. Routines provide a sense of stability at anxiety-provoking times. Keep reminders of the person who has died around the house e.g. photographs or a few belongings.

Support the person to move forward too, perhaps by encouraging them to explore new activities.

Support and encourage the person to remember and talk about their loved one on special occasions like birthdays and Christmas.

Support and encourage the person to visit the grave or a special place of remembrance if they want to.

A quick reminder:

Do

Use simple language to discuss what has happened.

Be patient - make yourself available to listen or help.

Acknowledge their loss and say you are sorry about what has happened.

Allow them to express their pain and unhappiness.

Reassure them that they are not to blame

Take the lead from the person, if they don't want to talk that is ok!

Don't

Avoid the person because you are uncomfortable - this can cause them more pain.

Tell them what to do or how to feel.

Change the subject when the loss is mentioned.

Point out that they should be grateful to have other things in their lives.

Don't assume that everyone needs help. Some people will cope with the grieving process with minimal support.



COVID-19 APPROVED GUIDANCE

OFFICIAL SENSITIVE

Note: This guidance has been fast-tracked for approval for use within NHSGGC

Covid-19 Bereavement Guide for Family and Carers of People with Learning Disability

This guidance is intended to assist healthcare professionals in the choice of disease-specific treatments.

Clinical judgement should be exercised on the applicability of any guidance, influenced by individual patient characteristics. Clinicians should be mindful of the potential for harmful polypharmacy and increased susceptibility to adverse drug reactions in patients with multiple morbidities or frailty.

If, after discussion with the patient or carer, there are good reasons for not following guidance, it is good practice to record these and communicate them to others involved in the care of the patient.

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Important Note:

The version of this document on the Clinical Guideline Directory is the only version that is maintained. Any printed copies should therefore be viewed as 'Uncontrolled' and as such, may not necessarily contain the latest updates and amendments.