

# End of Life support for People with Learning Disabilities during Covid-19



**Information to support talking about death and dying  
during Covid-19 with people with Learning Disabilities  
provided by Barnet Learning Disability Service**

We know that talking about death and dying is a difficult subject to talk about with people with Learning Disabilities, even more so with the current concerns of Covid-19.

It is very likely that people with a Learning Disability are likely to lose people that are close to, either their family, friends or other service users that they have lived with. They may be unwell themselves and could be at the end of their life.

The purpose of this information pack is to:

- Provide some tips on communicating with people with Learning Disabilities around death and dying
- Provide some examples of tools you can use to communicate this with people with Learning Disabilities.
- Support with End of Life care and planning

Before having these conversations, here are some things you should consider:

- Does the person you are supporting have capacity to make important decisions about their end of life – have you completed a mental capacity assessment?
- Talking about death and dying can be difficult for everyone involved, you don't have to talk about everything in one go
- Ask the person who else they might want to be there when talking about death and dying
- Use methods of communication that will enable the individual to understand
- Think ahead about how conversations might affect the individual and how you will support them
- Be aware of how you are affected by grief and if you have experienced a recent bereavement or are struggling with loss, you may want to ask another staff member to lead on this.

## Top tips for Communicating with someone with a Learning Disability about death and dying

❖ Communication is a basic human right for **EVERYONE**.

❖ Communication is vital to every aspect of our lives. It impacts on our relationships, choice, control, emotions, self-esteem and self-expression.

❖ It is **FUNDAMENTAL** to our wellbeing and quality of life.

1. Before you start talking to the person, make sure you have their **attention**. Get into a position where they can **see you**, use their **name** and encourage them to **look at you**
2. Use **simple language** – avoid long words and abstract concepts
3. Use **short simple sentences** and give **one piece of information** at a time.
4. Give lots of **time** and **speak slowly**. Allow time for the person to process your message and communicate back to you.
5. Emphasise **key words** with tone of voice, pictures or signs. For example, “I’m here to **talk** about your friend **John**”
6. Where possible, make information **visual**. Use **gestures, signs, objects or pictures**. Visual information is more permanent than the spoken word and allows the person to ‘see’ the information, as well as to ‘hear’ it, supporting understanding.
7. Check the person has **understood** what you have said. If possible, ask them to repeat what you have told them.
8. **Accept and value all means of communication**, not just speech. For example, sign, gesture, vocalisation and facial expression.

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9. We know from previous pieces of work that people with Learning Disabilities prefer people to be open and honest with them – using words like **“death”** and **“dying”** is ok.





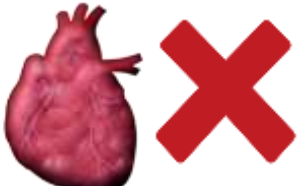
10. Discussion around death and dying should be encouraged with people with a Learning Disability, they have a right to know what is happening/has happened.

## Examples of ways to communicate

### Visual Stories to help with understanding

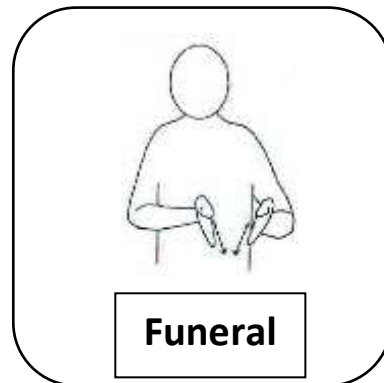
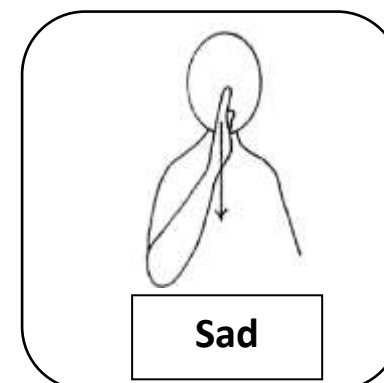
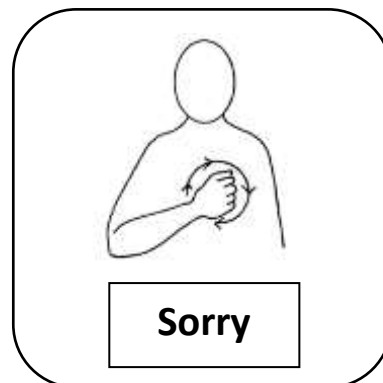
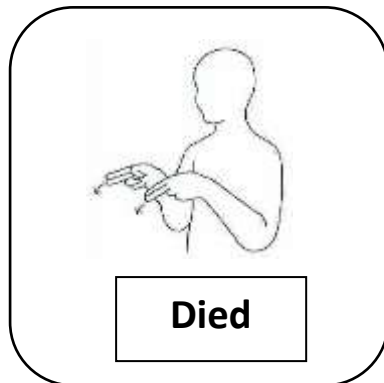
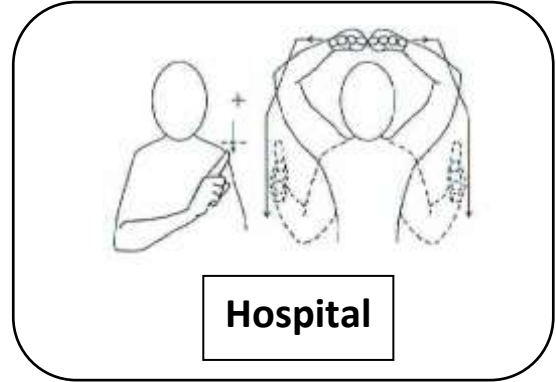
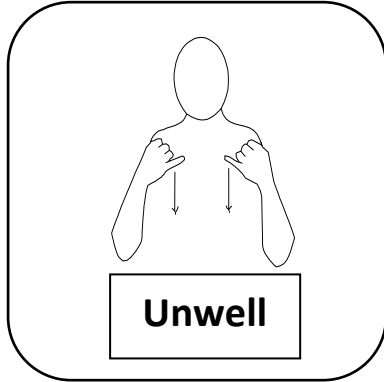
Not everyone you support will have much experience of death or dying and may need more support to understand more complicated topics. We have included below two visual; stories that may help with some of those.

#### A visual story: Dying from the Corona-virus

 <p>Corona virus</p>	<p>John has the Corona-virus</p>
	<p>John was very poorly</p>
	<p>John was taken to hospital</p>
	<p>John continued to be unwell</p>
	<p>John's heart stopped working</p>

	<p>John stopped breathing</p>
	<p>John died</p>
	<p>John will not be coming back</p>
	<p>This is very sad</p>
	<p>John will have a funeral</p>
	<p>To keep everyone safe from the virus not many people can go to the funeral</p>

## Useful Makaton signs



## Helpful questions to start the conversation



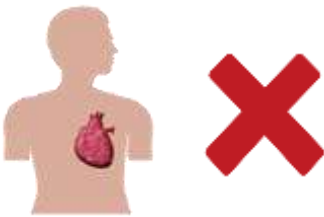
What is dying?



What do you think happens when you die?



Do you find it hard talking about dying?



If your heart stopped, would you like the Doctor to try and start it again?



Do you want to be buried or cremated?



What do you want people to remember about you?



Is there any special music you would like played?



What is resuscitation?



Do you know what's happened to xxx?



## **Caring for somebody who is dying from Covid-19 at home**

Supporting service users with a Learning Disability during Covid-19 is a challenging time, more so if you are having to care for a service user who is dying from Covid-19 within their own home. Using PPE can make this difficult time feel impersonal, so here are some things you might want to consider:

- Ensure the service user is where they feel most comfortable, this does not necessarily mean they should stay in bed, they may want to sit in their favourite comfy chair. They might want to be near the window or spend time in the garden
- Ensure their basic care needs are being met, i.e washing, dressing, continence care, eating and drinking etc
- Offer them foods they are their favourite and they can easily manage (if they can still eat)
- Have their favourite things around them, i.e photographs, music etc
- Ensure their communication needs continue to be met, i.e social stories, pictures, photograph or Makaton
- Make sure you have the medication required including “just in case” medications that would be prescribed for individuals who are palliative – do liaise with the GP or Community Palliative Care team if you don’t have these.
- Talk to their friends and family about planning a future celebration of their life, when people can come together again and Covid-19 restrictions have lifted.
- Keep in contact with the GP, Community Palliative Care team and anyone else appropriate, i.e family, friends etc

### **When someone has died and breaking bad news**

As mentioned on the previous page, supporting service users with a Learning Disability during this time is challenging. Even more so if you have found out that a service user within the home, or a friend or relative has died because of the virus (or perhaps for a different reason).

Here are some things that you might want to consider:

- Be open and honest with others think about the impact on that individual if they weren't informed their relative or friend had died.
- Think about how you're going to share this bad news: what is the person's level of understanding i.e does the person need to know why? What do they understand already?
- Who is the right person to deliver this news? Is there a support worker or family member who knows that individual better than others?
- How are you going to communicate this news? Some individual's may use verbal communication – be careful using language such as “passed away” or “fell asleep”, these can be too confusing. It is ok to use terms like “dead” and “died”.
- Some service users cannot understand verbal and non-verbal communications, so think about how else you would break the news? You could set up the service users bedroom, with a photo on their pillow; personal belongings around; perhaps some flowers and their favourite music playing. Allow them to visit the room in their own time.
- Attending a funeral is difficult, think how this could be re-created within the home: you could set up an area in the home where others can come and sit, using photos, flowers, candles and personal belongings. You could play their favourite music and speak about the person. If there are people that can attend the funeral then could they take photographs of the coffin? The chapel/church? Or the person being buried?

## Top tips on using the Mental Capacity Act 2005

### Assessing capacity

- Start off by thinking that everyone can make their own decisions
- The process is decision specific
- Give the person all the support you can to help them make their own decision, e.g using pictures, simple language
- Remember that people with a Learning Disability have the same rights as everyone else.
- People can make an unwise decision, doesn't mean they lack capacity
- Parents cannot make decisions on behalf of an adult, unless they have the legal authorisation to do so, i.e LPA
- The following format should be used:
  - 1) An individual must be able to understand information given to them
  - 2) Are able to retain the information long enough to be able to make the decision
  - 3) Weigh up the information given (pros and cons)
  - 4) Communicate their decision (speech, sign language, simple muscle movements i.e. squeezing a hand)



### Making a best interest decision



- If the individual is assessed as lacking capacity, then a decision should be made in the individual's best interest
- The decision made should be the least restrictive option
- Each decision is time and decision-specific
- Involve people in the discussion that know the person with a Learning Disability well, i.e. LD Nurse, GP, BLDS professionals, family and care provider staff
- The overall decision maker is the person who is requesting for the decision to be made
- An independent advocate should be involved in the decision-making process

**If you require any assistance with any of the above, please do not hesitate to contact the Barnet LD Team for further support.**

## Useful contacts

Who	How	When
Barnet Learning Disability Service	<b>Tel:</b> 02083596161 <b>Email:</b> <a href="mailto:BLDSIntegratedDuty@barnet.gov.uk">BLDSIntegratedDuty@barnet.gov.uk</a>	Monday- Friday 9-5pm
Care Quality Team	<b>Email:</b> <a href="mailto:CareQuality@Barnet.gov.uk">CareQuality@Barnet.gov.uk</a>	Monday- Friday 9-5pm
Social care Direct	<b>Tel:</b> 020 8359 5000 <b>Email:</b> <a href="mailto:Socialcaredirect@barnet.gov.uk">Socialcaredirect@barnet.gov.uk</a>	Monday- Friday 9-5pm
Emergency out of Hours (Social Care)	<b>Tel:</b> 020 8359 5000	Monday -Thursday 5.15pm-9am  Friday – 5.00pm to Monday 9.00am
North London Hospice	<b>Tel:</b> 020 8343 8841 (new referrals & patient related calls) Tel: 020 8343 6806 (General Enquiries) <b>Web:</b> <a href="https://www.northlondonhospice.org/">https://www.northlondonhospice.org/</a>	
Acute Liaison Nurses  Tamara McNamara Barnet General and Chase Farm Hospitals  Sarah Lally Royal free Hospital	<b>Mobile:</b> 07931 290623  <b>Tel:</b> 020 8216 4474 <b>Email:</b> <a href="mailto:tamara.mcnamara@nhs.net">tamara.mcnamara@nhs.net</a>  <b>Mobile:</b> 07903 225052 <b>Tel:</b> 020 7794 0500 ext. 39517 <b>Email:</b> <a href="mailto:s.lally@nhs.net">s.lally@nhs.net</a>	Monday- Friday 9-5pm
NHS 111	<b>Tel:</b> 111	Out of hours and weekends (when usual GP is not contactable)
Emergency Services	<b>Tel:</b> 999	When an emergency

## Useful resources

<u>Resources</u>	<u>Link</u>
<b>Books Beyond Words</b>	<a href="https://booksbeyondwords.co.uk/downloads-shop/when-someone-dies-from-coronavirus">https://booksbeyondwords.co.uk/downloads-shop/when-someone-dies-from-coronavirus</a>
<b>Covid-19, information for families</b>	 Covid 19, information for fami
<b>Symptom management</b>	 Symptom Management for Co

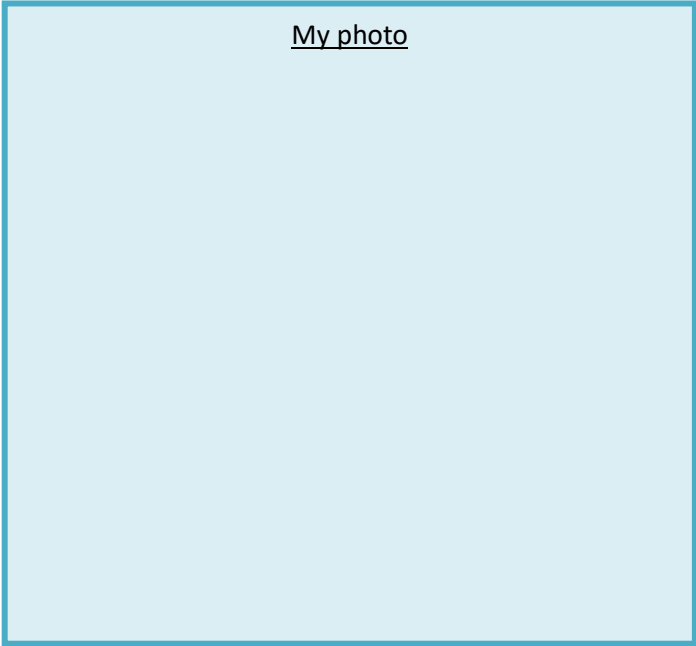
## **End of Life Planning**

Talking about the end of life can be very emotional, and this can be made more difficult for people with a learning disability who need additional support or communication strategies. We also know it can be difficult for you as support staff to have these conversations. But by having these conversations, you can help the person feel in control. Planning for the end of life means that we know that person will be getting the support that they really wanted. This is called an End of Life Plan, below is a template.

This is a link to a short video, looking at the importance of talking about death with someone with a learning disability: <https://www.caresearch.com.au/TEL/>

# *My End of Life Care Plan*

My photo




This Care Plan was completed by:

Date completed:

Reviewed by:

Date of review:

<p>(Photo of me)</p>	<p><b><u>Personal details</u></b> Name: DOB: NHS number: Address:</p>
	<p><b><u>What is my condition? Why do I need an End of Life care plan?</u></b></p>





**Decision making**

Do I have a DNAR (Do Not Attempt Resuscitation) order? Has a capacity assessment been completed (if needed), date completed and who was involved in this decision:

Do I have any Advanced Directives in place? Has a capacity assessment been completed (if needed), date completed and who was involved in this decision:

Do I have a Power of Attorney (health & welfare)? Who, and when was decision made?

Do I have a Power of Attorney (finance)? Who, and when was the decision made?

Do I have family/carers involved in my care? If so, who?

Do I have an Advocate? What have they helped me with?



**My final days**

Where do I want to stay in my final days?

Who do I want to be with in my final days?

Other wishes:



**What?**



**When I die**

What needs to happen?

Who should be contacted?

Do I want my organs to be donated? Has a capacity assessment been completed (if needed), date completed and who was involved in this decision:

What do I want to happen with my belongings?



**Funeral wishes**

Burial/cremation:

Where funeral to take place:



Do I want music? If so, what?



Do I want flowers? If so, what?



Do I want religious readings? If so, what?



Do I want singing? If so, what?



Do I want somebody to speak at my funeral? If so, who?



**Religious/Spiritual views**



**Contact details (family, carers etc):**

My GP:

Hospice/Palliative Care Team:

Family/friends:



Care Provider:

Professionals involved:

Advocate:

**Checklist – what needs to happen when I die**

We know that supporting someone to die is difficult for all those involved and remembering all the important things to do can be hard when you might be upset. Here is a list of things to remember:

<b><u>Action to be completed</u></b>	<b><u>Date/time/by who</u></b>
Inform my GP	
Inform my family/carers	
Inform my friend/people that I lived with	
Inform Barnet Learning Disability Service Tel: 0208 359 6161 Email: <a href="mailto:BLDSIntegratedDuty@Barnet.gov.uk">BLDSIntegratedDuty@Barnet.gov.uk</a>	
Inform any professionals involved in my care	
Inform CQC	
LeDeR notification to be completed <a href="https://www.bris.ac.uk/sps/leder/notification-system/">https://www.bris.ac.uk/sps/leder/notification-system/</a>	
Please follow own “Death reporting” protocol within your service	

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This document was produced by Barnet Learning Disability and Central London Community Healthcare NHS Trust.

Due to the frequent changes to the current COVID situation, we would recommend staff check information with latest government guidance.

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In addition, the information does not constitute a recommendation or endorsement of any organisation, resource or website listed.