

# Talking About Dying Survey

The experiences of staff  
talking to people with learning disabilities  
about death, dying and bereavement



## Results and top tips

January 2019

## What is the Talking About Dying Survey?

This online survey was sent to staff working with people with learning disabilities in residential and supported living services across the UK. It was developed by a team of researchers at universities in London, Cardiff, Glasgow and Ulster (*for details, see page 26*).

We wanted to know:

- How much are staff confronted with death, dying and bereavement at work? (i.e. a person with learning disabilities is dying, or is bereaved)
- How do staff communicate about death and dying with the people they support?
- How do staff cope with all this?

The survey had mostly multiple-choice questions, but there was also space for staff to tell us about their experiences and opinions in more detail. All the quotes in this document are taken from the survey responses.

### Who was the survey for?

The survey could be filled in by any frontline staff, regardless of whether or not that team had experienced the death or bereavement of a person with learning disabilities.

- If they had no such recent experience, we only asked them questions about their general opinions and training about death and bereavement.
- If they had recent experience (in the past 12 months) of a person with learning disabilities dying, we asked them questions about that person.
- If they had recent experience of a person with learning disabilities whose relative or friend had died in the past 12 months, we asked them questions about that person.

### Who took part in the survey?

Twenty-five service providers signed up to take part in the survey (*for details, see appendix 2*). With the help of the managers in these organisations, the survey was sent to 1,130 frontline staff, who filled it in anonymously. We received 690 completed surveys (an excellent response rate of 61%). These came from all four countries and all parts of the UK. Between them, these staff supported over 6,000 people with learning disabilities.

Here are some details about the staff who filled in the questionnaire:

- **Job:** About 3 out of 10 were frontline managers; 7 out of 10 were support workers.
- **Work experience:** Almost half had worked with people with learning disabilities for more than 10 years, and a further quarter between 5 and 10 years.
- **Sex:** About three-quarters were female
- **Age:** About half were aged over 45
- **Ethnicity:** Most (9 out of 10) said they belonged to a White ethnic group
- **Religion:** Just under half were Christian. About a third said they had no religion. Small numbers of staff said they were from other religions, atheist, agnostic or humanist.

## How representative are the respondents of the entire workforce?

We are not sure about this. It seems that the survey was sent to, and completed by, the more experienced team members.

We asked managers to send the survey to one member of staff (and not necessary the most experienced member) in ALL their homes/teams, even if there had been no deaths or bereavements. However, we think that some managers may have selected staff specifically because of their experience with death, dying and bereavement. We also think that staff were more likely to do the survey if they had experience of death and dying at work, or if they were interested in the topic and happy to think about it.

When looking at the results, it is important to remember this. It may be that other members of staff (for example, those who are not keen to do a survey about death) would have answered differently.

Overall, we found that staff (and indeed their senior managers who helped us distribute the survey) showed great enthusiasm for the survey, and interest in the topic of death and dying.

Thank you very much to everyone involved! (there is a list of all participating service providers at the back).

## The following sections give the survey results about:

- **People with learning disabilities who are dying** (page 4)
- **People with learning disabilities who are bereaved** (page 13)
- **Staff experiences, opinions, training and support needs** (page 22)
- **Useful resources** (page 25)

More detailed information about the results (including precise numbers/percentages) will be published in academic journals.

**Important conclusions and top tips** for staff and managers are in grey boxes.

*There is also a separate document with just the top tips.*

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**End of life is so important,  
we only have one chance  
to get it right**

## People with learning disabilities who are dying

### How many staff have recently supported someone who died?

- 162 staff (that's about a quarter) said that one or more of the people with learning disabilities they worked with had died in the past 12 months.
- Most of these deaths were expected by staff. About a quarter said that the person had died suddenly.
- 59 staff said that somebody was terminally ill currently.

In total, **152 staff** gave us further information about one person with learning disabilities who had died recently (where their death had been expected), or who was currently terminally ill.

*Remember* that we can't say for sure how many people with learning disabilities have died within these learning disability services. Staff will have been more likely to do the survey if they had experience of a recent death. It is also possible that more than one staff member completed a survey about the same person who died, so the answers below are not necessarily about 152 different people with learning disabilities.

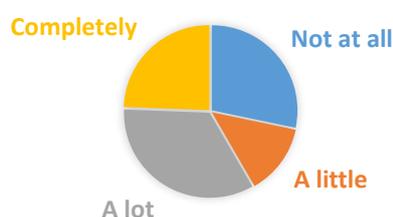
In the first year of supporting people, I have supported someone who has had a bereavement in their family and I have supported someone who eventually died. It was the first time I have ever seen anybody go through the process of dying.

I have managed 3 services over period of 3 years and had 4 deaths in total

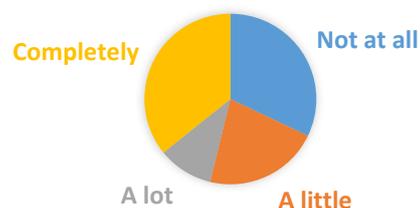
### What 152 staff said about the people who had died (or were terminally ill)

- **Age:** Most were between 50 and 69.
- **Ethnic group:** Overwhelmingly white British/Irish.
- **How long had they lived here?** Almost three quarters had lived in their current home/residential care setting for more than 5 years.
- **Living alone or with others?** Most lived with at least 3 other people. Fewer than 1 in 5 lived on their own.
- **Additional information:** Many of the people staff told us about also had autism, mental health conditions, or showed challenging behaviours. About a quarter had dementia.

## What staff said about the person's ability to understand and communicate



*Is the person able to understand what is said to them, and make themselves understood?*



*Does the person understand the concept of death?*

### Services need to be prepared for death

- **Death and dying happens in learning disability services!** It may not happen for many years, but most long-term staff are likely to experience the death or terminal illness of someone they work with.
- The people who are dying may have **severe and complex support needs, difficulties with communicating and difficulties with understanding.**
- **Services need to ensure their staff are prepared** for coping with terminal illness and death. It may not be necessary to prepare all staff for providing end of life support, but thinking about how to support people throughout the life span (up to, and including, death) is important for all staff.
- **How services can be prepared** will depend on the service itself, its staff and the people it supports. It could include, for example:
  - **Thinking about people's likely future care and support needs** (e.g. might changes in accommodation be needed, because bedrooms are upstairs and there is no lift? Might there be a future need for increased staffing?)
  - **Helping all staff to talk about death and dying**, and encouraging them to do the same with people with learning disabilities (for example, by using illness and death in TV soaps as talking points)
  - **Ensuring that there are experienced (and/or trained) staff within the organisation** who are confident in supporting people at the end of life, and who can provide tailored support to staff teams when needed. Supporting people at the end of life is difficult on many levels (practical and emotional). Staff will gain confidence from having someone confident they can turn to for help and advice.
  - **Getting to know the local palliative care team.** They may be able to support staff teams and give them confidence.

## Talking about illness and dying

### What was the person told about their illness and dying?

This shows how many staff said that the person was told...



*About their illness and what was wrong with them*



*That they would not get better*



*That they would die*

- Almost half of the staff thought that the person didn't realise they were dying; about a third thought they *did* realise it.
- However, a lot of staff (about 1 in 5) were not sure what, or how much, the person was told.

When all treatment was withdrawn and she was made comfortable and the sedation had worn off, I think she had some awareness of how unwell she was and having so many people around her (her family didn't usually visit her). I don't know if she understood that she was actually going to die though.

Personally, I think he DOES realise this. I think that this knowledge combined with inability to move/eat/toilet himself is profound, though he is incredibly stoic.

### Talking about dying... Why?

The most common reason for (trying to) talk to the person about the possibility of dying was related to their personal rights.

- "They have a right to know" came out top.
- The other main reasons were that the person could then be involved in making decisions about their care, help plan their funeral or decide about their bucket list.
- Less common reasons were that the person asked, or that they coped better if they understood what's happening.
- About 1 in 6 staff said they actively tried to create opportunities to allow the person to talk about being ill.

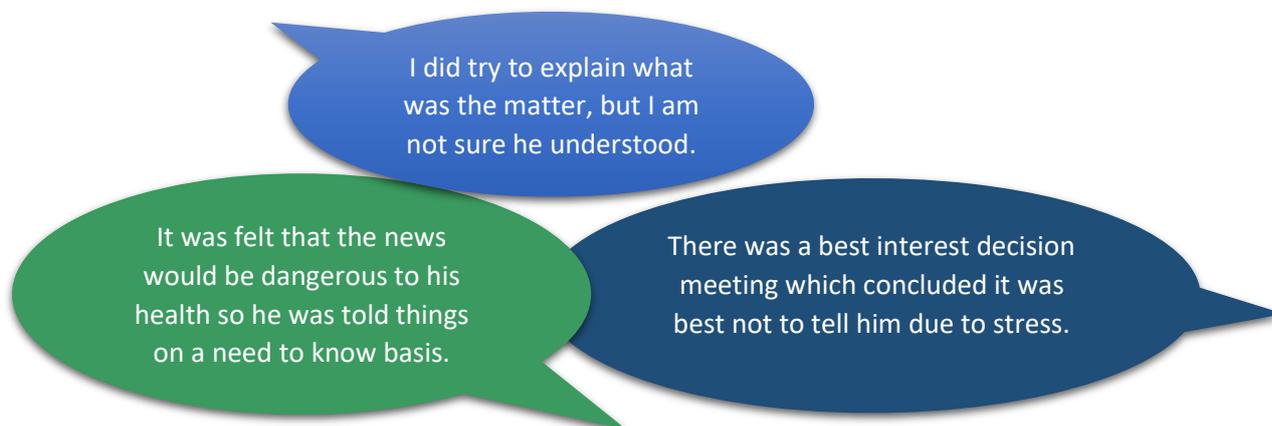
We explained everything but there was no evidence he understood.

She has been present at all meetings with oncology and has asked pertinent questions.

## NOT talking about dying... Why not?

The reasons staff gave for not talking to the person about the possibility of dying were more diverse.

- The most common reason was that the person would not understand.
- Some staff thought it best not to talk about dying, although they were honest about being ill and/or that it would be too upsetting for the person.
- About 1 in 10 staff said that the family didn't want the person to be told.

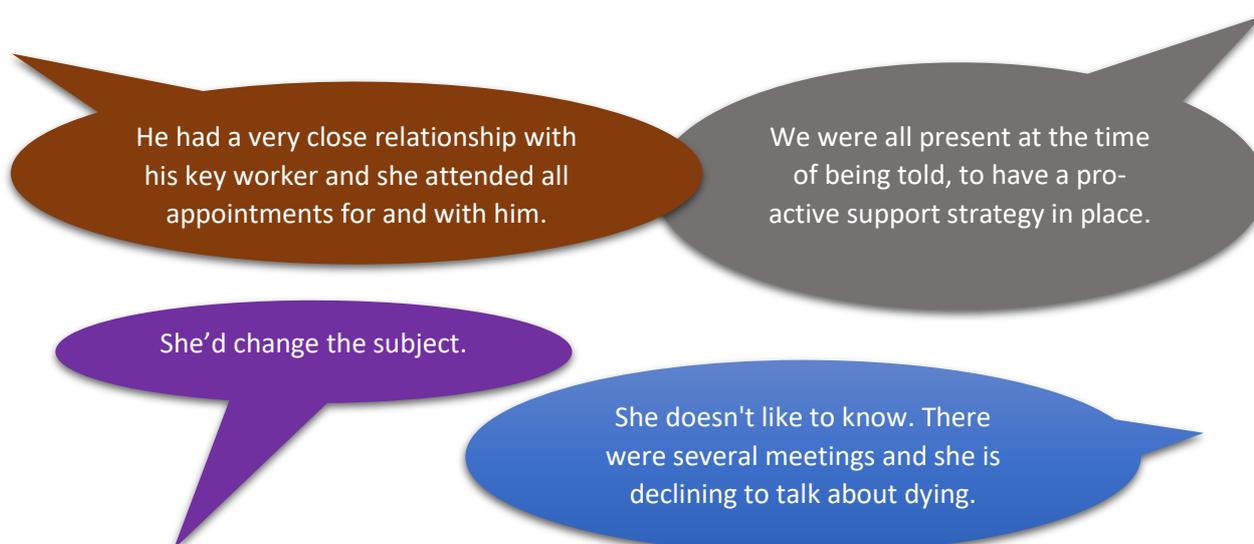


## Who were the key people to decide what to tell the person?

- Over half of all staff thought that doctors and family were the most important people to decide this.
- Managers were also important (about a third of staff thought this).
- Nurses and Community Learning Disability Teams were mentioned by 1 in 6 staff.

## Was the person was given the right amount of information, at the right time?

About half of the staff said yes, but a third of all staff were not sure about it.



Staff would verbally acknowledge when he suffered 'bad days', giving words of comfort. A discussion was never held regarding his life expectancy.

I have tried using films and stories to introduce the subject, but he demonstrated, by looking away, or putting his head down, that he did not want to 'talk' or 'think' about it.

### Talking about illness and dying with people who are terminally ill

- **There is a lot of uncertainty even among experienced staff** about whether and when to talk about illness and dying with people who are terminally ill.
- **There should be clear decisions** about whether, when and how to talk to the person about their illness and dying, and who should do this.
- **Managers, doctors and families are likely to have a key role**, but all staff need to know what the decisions are around disclosure.
- **It helps if everyone involved (including families and doctors) agree** about what the person should be told. If different people tell the person different things, it will be very confusing for them.
- **It can be very hard to know whether, and how much, the person understands.** Teams should talk about this, and agree together what their approach is. How much do they want to try and help the person understand? How important is it that they understand?
- **Talking is not the only way to help people with learning disabilities understand that they are very ill and dying.** Many people make sense of their situation through experiences, such as their body feeling more ill and tired. You can support the person by affirming those experiences, and not “jolly them along” or suggest that everything will be OK.

Remember:

- **People have a right, but not a duty to know about illness and dying.** If they do not want to talk about it, it is important to respect this. It may not be the right time (yet) – but keep the door open.

## End of life care

### Planning ahead

We asked who ever discussed the person's own preferences about treatment, care, bucket lists, where they would like to die, funeral wishes, and what should happen after death.

- Families and staff/professionals were seen as the most important.
- Most **families** were involved in discussing funeral wishes and what should happen after death. Many families were also involved in discussing care and treatment preferences, preferred place of death and bucket lists.
- **Staff and professionals** were mostly involved in discussing care choices (for example: lots of cups of tea, or only female staff to help me in the bath). They were also seen as equally important in discussing treatment preferences and place of death, but less important than families in discussing funeral wishes and what should happen after death.
- **The person themselves:** Relatively few staff said that the person was involved in talking (or otherwise indicate their wishes) about treatment and care, bucket lists, place of death (19%) or what should happen after death. Slightly more staff (around a quarter) said the person had communicated about funeral wishes.
- **Was the person as involved as they would have wanted?** About half of all staff said yes, but a third were not sure about this.
- **Did the person have a last will and testament?** Very few staff said yes. Most said no, but many were not sure about this.
- **Documenting wishes or preferences:**
  - About a quarter said that none of these were recorded in the person's notes.
  - Easy-read Advance Care Planning documents were used by a third of staff; most of these said the document had been produced or adapted specifically for the person.
  - Funeral wishes are most likely to be recorded; bucket lists and treatment choices least likely.
  - Quite a few staff, however (a third) were not sure about documentation.

He was told if he didn't stop smoking, comply with medication and make positive choices he would die.

We wanted her to be fully involved in all decision making about her health and well-being. We had a designated staff member that took on the role of keyworker and (for continuity purposes) attended all appointments with the individual.

She explicitly said she didn't want to know when it was going to happen. She was aware that treatment was stopped as it no longer worked.

## Who were the key people in making sure the right decisions were made?

This was perhaps more difficult to answer (more than a third of staff left this blank). Of those who did answer:

- Most said that it was a family member, and to a much lesser extent, a doctor.
- Fewer than 1 in 10 staff thought that they themselves, their manager or someone else in their team (such as a key worker) were key persons in the decision making process.
- Free text comments showed that some staff thought they (rather than the family) should have had more input.

Family took over most decision making which staff and management disliked. I personally think he would have done well with more decisions and may have helped him cope better at the end.

## Who were the most helpful professionals involved?

- Most staff mentioned a **multi-agency team** with a wide range of healthcare professionals.
- **GPs and doctors** were singled out as particularly helpful.
- A quarter of staff said there had been involvement of a **hospices or palliative care team**.

## Did you get enough support?

- **Support from managers:** Most staff (9 out of 10) said that they had received full or partial management support that helped them to support the person in their final illness. Fewer than 1 in 10 said that they hadn't been supported enough by their managers.
- **Support from outside professionals:** This was also positive, with 8 out of 10 staff saying they received such support.

## How much did you talk with your colleagues?

- The majority of staff (9 out of 10) said that they had talked about the illness, death and dying with their colleagues, both in team meetings and informally. Many of these said that they talked about it a lot.
- The rest of the staff said that they had not talked much (or at all) about it with colleagues.
- Most staff said they had talked as much as they wanted to. Some would have liked to talk more, but hardly anyone would have liked to talk less.

We didn't have regular team meetings.  
We all needed more support but workers tried to support each other.

We had someone come to the office for a team meeting, who went through palliative care with us. This opened the door for us all to talk a lot more about what was in front of us. It was good to know we could talk about to each other and support each other through what was ahead.

## What would help

Most staff (about 9 out of 10) thought that all of the following would be very useful:

- **Knowing we can ring someone at all times**, to ask for help and advice (such as a GP or hospice nurse).
- **Home visits from outside professionals** (such as a GP or hospice nurse).
- **Practical support from the manager and organisation** (such as making sure that there are enough resources and staff).
- **Staff training:** on bereavement, breaking bad news, communication, end of life care and advance care planning.

To be able to ring health care professionals at any time without being made out to be stupid or you don't know your job. Also to get more support from our line manager & regional manager and again not be made to feel low about the decision of ringing them. A little extra support goes a long way in these situations as sometimes being the advocate on behalf of service users is very stressful.

The supporting medical staff were absolutely wonderful ...the oncologist Dr and Mcmillian nurse went over and beyond their duties. This helped the most.

I was informed that individual had passed away but there was minimal support around how I was feeling. Although my role has professional boundaries it's very difficult not to become attached.

## Providing end of life care

- **Choices and decisions:** There are a lot of choices and decisions to be made with regards to the end of life, including decisions about treatment, care, best place of care and place of death, bucket lists, funeral wishes and what should happen after death.
- **Staff are involved in helping to make these decisions**, but do not see themselves as key in this process. They believe that families (and, to a lesser extent, doctors) are most important. Good working relationships with families are therefore crucial.
- **Most people with learning disabilities are not involved themselves** in making choices and decisions. It is difficult to know whether this is because they lack the ability or capacity, or for other reasons.
- **If the person lacks capacity**, multi-agency meetings (also involving the family) are particularly important in establishing what is in the person's best interest, and what their wishes would be.
- **Staff need practical support.** Providing end of life care is likely to be stressful. The person's care needs may increase, so higher staffing levels are probably needed.
- **Ensure that outside agencies are engaged.** Other research has shown consistently that end of life care is best when learning disability services, primary care and palliative care services work together.
- **Supporting a person towards the end of life can be scary.** Make sure that staff know exactly who they can call for help, support or advice, at any time of the day or night.
- **Hospices and palliative care teams:** All people who have an illness or condition from which they are likely to die can be referred to a palliative care team. (The GP can arrange this, but it is also possible to contact hospices directly.) Hospices can be involved even if the person is not (yet) dying. They will do home visits and support the person to stay at home, if that is preferred.
- **Staff need emotional support.** They often feel close to the person and are affected by the situation. When the person dies, staff can feel bereft. It helps to acknowledge this.

The support I received from my team facilitator and service manager was next to none. They were always had the end of the phone if I needed someone to talk too. Even on my days off if I needed a chat, I would meet up with my team facilitator for a coffee.

The family of the person we supported asked worker to stop visiting three weeks before he died and only family saw him after this. We worried that he would think we had forgotten about him.

My employer is very good, lots of efforts are made to do the right thing, but due to the level of disability the question I ask is, how we know it is the right thing?

## People with learning disabilities who are bereaved

### How many staff have recently supported a person who was bereaved?

This means that a relative, close friend or housemate has died in the past 12 months.

- 309 staff (that's almost half) said that one or more of the people with learning disabilities they worked with had been bereaved in the past 12 months.

In total, 201 staff gave us further information about one person with learning disabilities who had been bereaved recently.

(Again, remember that this is not necessarily 201 people with learning disabilities. Some of the staff surveys may have been about the same person.)

In the last 11 months he has lost his sight, independence as unable to go out by himself now, his mum, his home. Has had to move into supported living because unable to live safely by himself. He is grieving for everything that he has lost.

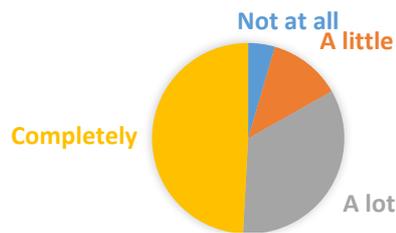
When meeting staff he asks which members of the family are alive and dead. I think this is due to his mum and dad dying.

He believes that dad is having a great time in heaven doing all the things he wants to do and seeing everyone else who has died, even Princess Diana.

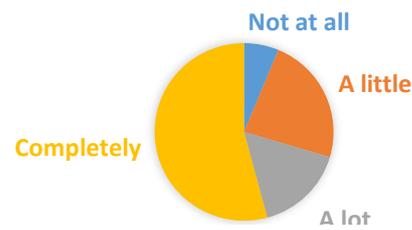
### What 201 staff said about the people who had been bereaved

- **Age:** Bereavement happened to people in all age groups. Almost half were between 40 and 59; a third were younger.
- **Ethnic group:** Mostly white British/Irish.
- **How long had they lived here?** Most had lived in their current home/residential care setting for more than 5 years. A quarter had lived there less than 3 years.
- **Living alone or with others?** This varied widely. About a fifth lived alone; others lives with 1, 2, 3 or more people.
- **Additional information:** Many staff said that the person had autism, mental health conditions, or challenging behaviours. Dementia was reported less often.

## What staff said about the person's ability to understand and communicate



*Is the person able to understand what is said to them, and make themselves understood?*



*Does the person understand the concept of death?*

Overall, compared to the people who were terminally ill or had died, the bereaved people were:

- Younger
- More likely to live on their own, or with just 1 or 2 others
- Twice as likely to have autism (we have no explanation for this)
- Much more able to do things independently
- Much better able to understand and communicate

Still asks to see her Dad regularly, but when explained Daddy is in heaven, she shows empathy saying he is poorly.

She thinks they come back to live.

He asks "Does my mum know she's died?" "Where has she gone?" "Does she know she's buried?"

## Who died?

- Over three quarters of staff said that the person's **relative** had died.
- The vast majority of these relatives were the person's **father or mother**, but it also included siblings, grandparents, aunts or uncles.
- The rest of the staff said that the person had been bereaved of a **friend or housemate**.
- Almost all bereaved people used to have **regular contact with the person who died**. Half of the staff said that the bereaved people used to be in contact with that person every day, or at least once a week.

## Bereavement is common!

Even accounting for the fact that staff were probably more likely to complete the survey if someone they supported had been recently bereaved, it seems that bereavement is a common occurrence among people with learning disabilities in all age groups.

- The losses they face are significant.
- Parental loss is often particularly life-changing.
- The bereaved people with learning disabilities were often close to the person who had died, with regular contact.

### Services need to be prepared for bereavement

- **Very many people with learning disabilities face significant bereavements.** Many people will have to cope with the death of a parent, for example.
- **Bereavement has a huge impact** on people's lives. It can also have a significant impact on people's mental health.
- **Grief is often under-recognised** in people with learning disabilities. They may express grief atypically, or late – even several years after the death.
- **Most staff are likely to experience the bereavement** of someone they work with.
- **Services need to ensure their staff are prepared** for coping with bereavement.
- **All staff should be familiar** with the different ways in which people with learning disabilities might express grief (for example, withdrawal, anger, or unusual behaviour).
- **Many people with learning disabilities are able to understand death and dying**, but that does not necessarily make supporting them through bereavement easier. Death is difficult to understand for everyone! The staff comments show how difficult the questions can be that people ask them.
- **Explaining death** is difficult. It is important to know how the person makes sense of death (e.g. do they think people go to heaven?)
- **Use the person's own vocabulary** about death. Beware of euphemisms (e.g. "We lost Dad"; "He has gone to a better place"). Are you sure that the person understands them in the same way as you do?
- Staff should talk in their teams about **how they themselves understand death**, and how they would explain it to others. Are we imposing our own belief systems on others?

### Who decides what the person should be told?

- The majority of staff thought that a family member was key in deciding what to tell the person about the death. This was especially true of the person's learning disabilities were more severe.
- Many staff also thought that members of their team (such as a key worker, their manager, or indeed themselves) had an important role in deciding this.
- Doctors or community learning disability teams were not seen as important.

## Who helps the person understand?

- Families were seen as important here too (two thirds of staff thought so)
- Staff saw themselves and colleagues as equally important.

All staff will talk with him if needed.

Anybody who has worked personally and has a strong, good relationship with the individual.

It is his immediate family's decision on when and how much info he would be told, us carers including the line manager have a close relationship with the family and as a team we would all have a little input on how we feel it would be best to tell him.

## If the death had been expected...

### WHO expected it?

Most staff said the person who died had been unwell beforehand, so their death was not unexpected. We asked further questions about these expected bereavements:

- Of everyone involved, the person with learning disabilities was least likely to realise beforehand that their relative/friend was likely to die. Staff thought that over half of all families probably knew, but only 1 in 10 people with learning disabilities did.

### Talking about the possibility of the relative/friend dying... Why?

There was a wide range of reasons why anyone had ever tried to talk with the person with learning disabilities about the fact that their relative/friend might die. Staff said that the person:

- had a right to know,
- indicated that they wanted to know or talk about it,
- coped better if they understood what was happening,
- were then able to spend quality time together and say goodbye,
- or that the family wanted them to be told.

I have a person that we support who's dad is ill at present so will need to do this at some point and have found no help in trying to explain to him what is happening.

## NOT talking about that possibility... Why not?

- The most common reason for not talking about this was that staff themselves didn't realise the relative/friend was likely to die, or that they were not completely sure how long that person would live, so they couldn't give clear information.
- About 1 in 8 said that the person wouldn't understand.
- About 1 in 8 said that the family didn't want them to be told.

The family knew and chose not to tell her as they didn't want to upset her when she was visiting the parent.

I personally feel a lot of people can be in denial and want to avoid the "hard" conversations. In the last six years I have supported four people who were not told how poorly their parents were so it was such a shock for them when the parent actually died.

### Telling people with learning disabilities that a loved one is going to die

- If the person does not know that their relative or friend is expected to die, they will **experience the death as a "sudden death"**. This is often more difficult to cope with.
- Knowing that a parent (or other loved one) is going to die is very sad, but **sadness is not, in itself, a good enough reason** to withhold such knowledge.
- Knowing that a loved one is going to die **allows the person to spend time with them** and say goodbye.
- **Some people do not cope well with uncertainties** (such as not knowing exactly *when* the person is going to die). This is particularly true for people with **autism spectrum disorders**. Think carefully about how to talk with them about what will happen in the future. It may help, for example, to go through a script ("We don't know when Dad will die, but when he does die, this and this and this will happen"). This can help in preparing someone to cope with what will be an upsetting time.
- **Talking is not the only way** to explain what is happening. Visiting the ill person or, better still, involving the person with learning disabilities in caring for that person, can be extremely helpful.

## When someone has died...

### How soon after the death was the person told about it?

- Most staff (about two thirds) said the person was told immediately.
- Hardly anyone had not (yet) been told.

### Reasons for not telling the person immediately

- In almost half of these situations, it was because the staff didn't know about the death either.
- A quarter said that the right person to tell was not available.

His mum wanted to tell him but needed a day or two to think the best way to tell him.

Her brother wanted to be the one to tell her in person and he could not come straight away.

Staff who know her well were on shift the next day.

### With regards to communicating about death, staff said that most staff and relatives...

- Try to keep things positive at all times.
- Try to support the person to express feelings or distress.

Most staff tended not to **initiate communication about the death**. Many said they only talk about the death if the person brings it up themselves.

It was something that would be spoken about each day. Then after about two weeks it was never mentioned and hasn't been since.

He will say that he hasn't seen his uncle in a while and can we help to arrange a visit. We try to distract.

Mentioned once or twice, but I have neither tried to take her mind off it nor encouraged her to talk about it more, I simply listen.

She is not able to communicate verbally, though staff talk to her about the person who has died.

## Talking about death with people who are bereaved

- **Most staff want to support the bereaved person** as well as possible, but they are sometimes unsure how best to do this.
- **Death is deeply distressing.** This is true for all of us. It is important to allow people with learning disabilities to be distressed or upset – including at funerals.
- **Many bereaved people are helped by opportunities to remember the person who died.** Staff could help to create opportunities for remembering. This could be both informal (e.g. talking about the person who died) or formal (e.g. organising remembrance events).
- **People with learning disabilities may not initiate conversations** about their bereavement, but that doesn't mean they don't want to talk about it. Staff can help by mentioning the dead person in day-to-day conversation, helping the person to share memories etc.
- **Be sensitive to the person's needs.** Not everyone wants to talk about, or be reminded of, the person who died. If they do not want to talk about it, it is important to respect this. It may not be the right time (yet) – but keep the door open.
- Be aware, though, that distress does not necessarily mean that it's better for the person not to think about the loss.
- **Rituals, photographs, objects, smells and sounds** can all help people to remember the person who died, including people who don't use words. It might even be possible to plan for this, for example, by audio-recording an elderly parent talking or singing their favourite song.
- **Celebrate lives and legacies.** Consider actively creating time and space to think about, talk about and remember the person who has died. Invite friends and families.

Talk about it when she wants to talk about it, and always try to keep it positive, e.g. her father is now with her mother in heaven and looking after each other and watching over her.

Sometimes he gets upset, but if you ask "do you not want us to talk about your mum" he says he does want to talk about mum.

He has a book about his relative and will bring it out to staff if he wants to talk. When completing his room care staff encourage him to polish his photos and talk about his relative.

She has a rose bush in the garden that she planted for him which she often goes out to. She also has a pillow with a picture on it of her with her dad. She has that in her room and sleeps with it. She often brings out her pillow to hug it.

## The funeral

- Two thirds of staff said the bereaved person **attended the funeral**.
- For those who **didn't attend**, the most common reasons were:
  - The family didn't want them to go
  - The person didn't want to go
  - It would be too upsetting
- About 1 in 6 staff said that the bereaved person was involved in **planning or preparing the funeral** (such as selecting music, carrying the coffin, help to invite guests etc).
- Very few staff said that the person **viewed the body**.

The family thought it best to exclude him from the funeral arrangements. They organised the funeral and flowers. He didn't go to the funeral.

She assisted her sister, her sister kept her involved and they read a poem out together at the funeral, and she suggested some of the music.

The family was afraid that perhaps he will be upset and exhibit challenging behaviours which might disrupt the funeral.

Overall, it seems that most people with learning disabilities are told that their relative or friend has died, and most are given the opportunity to attend the funeral. This is excellent news – in the past, many people with learning disabilities were not told that a loved one (even a parent) had died, and often did not attend the funeral.

However, still relatively few people are given the opportunity to be involved in important mourning rituals such as viewing the body, or *participating* in funerals, even if it was the funeral of a parent.

### Funerals

- **Funerals are important mourning rituals.** They provide opportunities to share grief, and to see that everyone is sad and upset – it's not just you!
- **Learning about funerals** can start at any time. Consider the possibility of people attending the funeral of someone they are not particularly close to – so that when they attend the funeral of a loved one, they know a bit better what to expect.
- **Respect people's choice *not* to go to the funeral** – but make sure it's *their* choice, not that of family or staff.
- **Support the person throughout the funeral.** This should be done by staff who know the person well. Talk to the family about this, too – they may be worried about their own (in)ability to provide support at such an emotional time.
- **Find ways of involving the person** in the funeral. This is particularly important, and poignant, for the funerals of close relatives, such as parents or siblings.
- **Consider taking photographs or videos** at the funeral, to help the person talk about it afterwards.

## Support for staff (to help the person cope with bereavement)

### Did you get enough support?

- **Support from managers:** About three quarters of staff said that they had received full or partial management support.
- **Support from outside professionals:** A third of staff said that they had received outside support, but among those who didn't, most said that they didn't feel the need for outside support.
- **Knowing that they can ring someone at any time** to ask for help and advice would be very useful. Three quarters of staff thought this.
- **Staff training:** Like the staff who had supported someone who had died, almost 9 out of 10 staff who had worked with a bereaved person would find it useful to have training on bereavement, breaking bad news, communication and end of life care.

### How much did you talk with your colleagues?

- A third said that they had not talked much (or at all) about the bereavement in team meetings, and a quarter said they hadn't talked much about it informally either.
- 1 in 7 would have liked to talk more; a quarter wasn't sure about this.

Overall, it seems that staff felt well supported within their own organisation. Managers and colleagues were good at helping them to cope with supporting the bereaved person.

I personally didn't think I needed additional support, and I can't fully answer for my other team members but to my knowledge they didn't feel as though they need extra support either. We are a close team who help and support one another.

Our staff team and managers were very supportive so we didn't need anyone else.

The doctors are dreadful where we are.

## Staff experiences, opinions, training and support needs

The following relates to questions we asked of all staff (including those who had not recently supported someone who was bereaved, or who had died). This was a total of 690 staff.

### How difficult is it to talk about death and dying?

- About a quarter of staff find this difficult. Almost half said that they find it easy.
- Staff who had recently supported a bereaved person were more likely to find it easy to talk about dying.

### How confident do staff feel?

Levels of confidence among staff were high, with regards to working with people who had been bereaved or were terminally ill.

- **Working with people who have been bereaved:** 8 out of 10 staff who had recently done so felt confident about this. Of those who had no recent experience, 6 out of 10 felt confident.
- **Working with people who are terminally ill:** 6 out of 10 staff who had recently done so felt confident about this. Of those who had no recent experience of terminal illness, slightly fewer felt confident.
- **Talking about death and dying with people with learning disabilities:** Confidence was highest among those who had supported a bereaved person (7 out of 10 felt confident), and slightly lower among those who had supported a terminally ill person (6 out of 10) or those without recent experience (5 out of 10).

We were pleasantly surprised to hear that so many staff feel confident, and so many find it easy to talk about dying. In the general population, many people find this quite difficult.

We think that the survey was answered by the most confident of staff. It may be useful for managers to check with staff (and with themselves!) how comfortable they feel about coping with death and bereavement, and with talking about dying.

I don't deal well at all with death so prefer not to talk about it.

I had previously worked in a care home for the elderly where I cared for terminally ill people and also cared for my own mother while she was dying of cancer. This is why I feel confident, but I would not have felt confident before these experiences.

## Training

### Have staff received guidance or training?

We asked staff if they had ever received any training and guidance on the following.

- **Working with people who are terminally ill or dying:** Of those who had recently done so, almost half had received training. Of those without recent experience, a quarter had received training.
- **Working with people who are bereaved:** About a quarter of staff had received training on this. Those who recently worked with a bereaved person were no more likely to have received training.
- **Breaking bad news:** about 1 in 5 staff had received training on this. The percentage of trained staff was lowest among those who had supported a bereaved person (16%) and highest among staff who had supported a terminally ill person (25%).

I would love to do end of life training, but extensive training, not online training.

Training would be useful, but not compulsory just to pay lip service to some tick box exercise. It would need to be meaningful and concise, with resources available. remembering to ascertain if the staff member would require the training would also be very important, they may have recently lost someone and training for training's sake could be too much to bear!

### Training and support for staff

- It seems that **experience increases confidence** among staff.
- **If a team does not have experienced staff members**, managers should ensure that they can draw on experience from outside colleagues or managers.
- All staff will benefit from **talking through issues around death and dying** with colleagues and managers.
- **Service providers need to consider the training needs** of all their staff, and how best to provide this training.
- This could include a **consideration of who to train**. Not all staff may need training in end-of-life care, for example, unless the situation arises. Outside professionals (such as palliative care teams) may assist with such training, so it is useful to make collaborative links.
- However, **all staff should have thought about the possibility of death and dying**, how this might affect the people they support, and how they themselves feel about it.

- **Bereavement training** should be given to all staff. Bereavement is a common occurrence, and all staff are likely to be confronted with this at work. They need to know how best to support people and how to talk about death and dying.
- **Some staff find it too difficult** to work with people who are dying or bereaved. It can be particularly hard if there is terminal illness, death or bereavement in their personal lives. This needs to be acknowledged. It may be necessary to rearrange staff duties if possible (for example, moving staff to a different team).
- **Managers should be aware** of the needs and experiences of their staff, including personal bereavement experiences, as this will affect their work.
- Consider **inviting families to training/learning events** about death and bereavement. Sharing thoughts with families can be very helpful. It will make it easier for families and staff to communicate about death and understand each other's perspective, when the situation arises.

In my view, it's NOT within my job remit to do that sort of care. I am a support worker, NOT a care worker. We have a lot of responsibility already... If I were to be asked to do end of life care for more than a very short period, to cover transition to more appropriate care workers, I would refuse.

Staff who work in care should have some training in dealing with bereavement/terminal illness etc as they are in the front line and dealing with clients daily. We may think we would be ok helping others but as we all have different ideas/ways of dealing with things, we may be causing more anguish.

As a team we all had our individual questions on how best to give full support and we all aired those within the service as they arose and a solution, advice or appropriate action was taken according to the issue that had arisen.

# Useful resources

## Websites

<http://www.breakingbadnews.org/>

Website on breaking bad news to people with learning disabilities, written by Prof Irene Tuffrey-Wijne.

- *Resources and guidance produced as a result of the Talking About Dying Survey are available on the “Tools and training materials” page*
- *An extensive list of relevant articles and other publications: see “Publications” page*

<http://www.pcpld.org/>

A website and network which has a mutual way of sharing information with regards to palliative care for people with learning disabilities. Includes a “Resources” page.

<https://www.caresearch.com.au/TEL/>

Australian website designed to help support staff teach people with learning disabilities about the end of life.

## Book

Tuffrey-Wijne I. How to break bad news to people with intellectual disabilities: a guide for carers and professionals. London: Jessica Kingsley Publishers; 2013.

## Books Beyond Words

Books Beyond Words is a series of picture books that has been developed to make communicating easier for people with learning disabilities, and to enable discussion about difficult topics. The pictures are designed to help the reader make sense of what is happening to them, and help them to ask questions or share their concerns. Supporting text and guidelines are also provided for carers, supporters and professionals. The website also includes a video and advice on how to use the books.

[www.booksbeyondwords.co.uk](http://www.booksbeyondwords.co.uk)

### Useful titles include:

- *Am I going to die? (about being terminally ill)*
- *When Dad died / When Mum died (about losing a parent)*
- *When somebody dies (about coping with bereavement, and bereavement counselling)*

## The Research Team

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*Left to right: Laurence Taggart, Janet Finlayson, Irene Tuffrey-Wijne, Jane Bernal, Stuart Todd, Claire Lam*

## Contact

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Twitter handle (used for announcing the publication of paper, films, training materials etc)  
**#TalkingAboutDyingSurvey**



Films related to the TalkingAboutDying Survey, can be found on this YouTube channel:  
**Prof Irene Tuffrey-Wijne**

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**The Baily Thomas**  
Charitable Fund



## The Research Advisory Group

The role of the Research Advisory Group was to offer support and advice on the development, piloting and administration of the survey, champion the survey within their own services, and promote the results of the study. The group had the following members:

**Annette Boaz** Professor in Healthcare Research, Kingston & St George's University

**Lester Bream** Advisor with learning disabilities, GRASSroots

**Celia Chandler** Learning Disability Support Worker

**Amanda Cresswell** Advisor with learning disabilities, Kingston & St George's University

**Jo Giles** Easyhealth Project Coordinator, Generate

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**Maggie McCaul** Quality coordinator, Mencap

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**Julia Shearn** Researcher, University of South Wales

**Monica Stannard** Family carer

**Bob Tindall** Managing Director, Dimensions UK

**Jean Willson** Family carer, Centre 404

**Rhian Worth** Researcher, University of South Wales



*Some members of the Research Advisory Group meet with the researchers to discuss the survey results. Left to right: Irene Tuffrey-Wijne, Bob Tindall, Amanda Cresswell, Celia Chandler, Tracey Rose, Annette Boaz, Claire Lam, Monica Stannard, David Jeffrey, Michelle McDermott.*

## Participating organisations

A huge thank you to all the staff who took part in the survey.

We have found your responses extremely helpful. Thank you especially to those who completed the survey despite finding it difficult, or despite being pressed for time.

These organisations participated in the survey:



I have found this survey extremely distressing, as I do not deal very well with death and bereavement, and having very recently lost a dear friend. I have however completed it.

Very good survey, thank you!