



The Victoria & Stuart Project

Evaluating a toolkit of approaches and resources for end-of-life care planning with people with learning disabilities within social care settings

We invite you to take part in a research study

- We are looking for health and social care professionals or care/support staff to **test an end-of-life care planning toolkit with people with learning disabilities.**
- **This information sheet** tells you more about what's involved, to help you decide whether or not to take part. There is a summary on the next page, followed by more detailed information.
- **You are free to decide** whether or not to take part in this study.
- **Ask us** if there is anything that is not clear or if you would like more information.

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Contact us

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www.victoriaandstuart.com

You can go to our website to find out more about:

- The whole project: what is it all about?
- How the toolkit was produced, together with people with learning disabilities, families, carers and staff
- All the people and organisations involved in the study

SUMMARY of this information sheet

1. **What is in the end of life care planning toolkit?**

Resources for funeral planning and for illness planning, recording sheets, plus guidance.

2. **Who should the toolkit be tested with?**

People with a learning disability, or (if they lack capacity to take an active part) their family/friends. You are also welcome to test it with people without a learning disability.

Funeral planning resources can be tested with anyone. **Illness planning resources** should be tested with people who are getting close to the end of life.

3. **Why have I been invited?**

We are looking for anyone working with people with a learning disabilities and people near the end of life, to try the toolkit and give us feedback, before we finalise it.

4. **What will I have to do in the study?**

- Familiarise yourself with the toolkit guidance (1-2 hours)
- Try out part of the toolkit with at least 1 person, at least 1x (you can do it more often)
- Give your feedback about each session, using an online form (30 mins)

5. **Do I have to take part?** No.

6. **Are there any risks for me in taking part in the study?**

Thinking and talking about dying can be upsetting.

7. **Are there any benefits for me in taking part in the study?**

You will get access to the new resources and the guidance, which will give you new skills.

8. **Will my information be kept confidential and secure?** Yes. Your information will be kept confidential unless someone is at risk of harm. We comply with all the GDPR regulations. Your information will be anonymised.

9. **Who has approved the study?** Social Care Research Ethics Committee (reference 23/IEC08/0033).

10. **Who is funding the study?** National Institute for Health Research (NIHR)

11. **Who do I contact if I have any concerns or complaints?** Prof Irene Tuffrey-Wijne (study lead).

Read on if you want to see MORE DETAILED information.

Alternatively, you can email the research team with any questions.

1. What is in the end of life care planning toolkit?

The toolkit is split into two main parts:

- **Funeral planning.** This has:
 - Pictures to support conversations about funerals
 - Cards with pictures to help people make choices about what they might want for their funeral
- **Illness planning.** This has:
 - Cards with pictures to help people make choices about what they might want when they are very ill and might die
 - A Books Beyond Words picture book: *Am I Going To Die?* (not available online; if you want to use this, you will have to purchase it [HERE](#))

Both parts also have:

- A way for recording people's choices, ideas and preferences
- Guidance about how to use all these

2. Who should the toolkit be tested with?

The toolkit is being developed for and with people with a learning disability. The resources should be introduced to them by staff, a carer or professional, who will support them to have conversations about illness, dying, death and funerals.

You are invited to test EITHER the funeral planning resources, OR the illness planning resources. If you would like to test both parts of the toolkit, that is possible too.

They can be used with the person with a learning disability themselves, or (if they are unable to understand or cope with pictures or find it too difficult to indicate their preferences) with their family/friends/supporters.

- The **funeral planning** resources can be tested with/for anyone who wants to.
- The **illness planning** resources should be tested with someone who *may* be nearing the end of life, for example, because:
 - They have been diagnosed with a terminal condition (e.g. cancer or dementia)
 - They are not terminally ill, but you wouldn't be surprised if they died within the next year (for example, because they are frail, elderly, or often unwell).

Can I test the toolkit with people who do not have a learning disability?

Yes, you are welcome to test the toolkit with anyone who you think might benefit. We are interested to hear how other groups of people (including the general population) get on with our new resources. This may give us an indication of whether the scope of the toolkit might be wider than people with a learning disability, which could then be further investigated in future studies.

If you use them with people who do not have a learning disability, please specify this on the feedback form.

Please note that the resources have not been pre-tested with any other populations, although families and health/social care professionals (including palliative care professionals) have been involved in the development.

3. Why have I been invited?

You are invited because you have expressed an interest in testing the toolkit. This may be because you support someone with learning disabilities who might be interested to think about funeral planning, OR someone who might need to think about planning for the end of life.

Before we release the toolkit, we want to listen to the experiences, thoughts and opinions of people who will use the toolkit. We want to know if the toolkit can help people to talk about what they would like to happen at the end of their life.

4. What will I have to do in the study?

Testers will:

1. **Receive a secure link to the toolkit.** They will be able to download the resources, but they will be asked not to forward the link or the downloaded resources to others.
2. **Familiarise themselves with the toolkit** before using it. You need to look through the resources, read the guidance, and watch some short demonstration videos (this will take around 1-2 hours).
3. **Find at least 1 person with a learning disability to try out some of the toolkit** with, or (if the person is unable to be directly involved in end of life care planning, for example,

because they have severe/profound learning disabilities), **ask their family/friends/staff who know them well to try the toolkit with you**. You can have as many sessions with the planner (or their family/friends) as you like. You can also use different parts of the toolkit at different times. (You are also welcome to try the toolkit with people who do not have a learning disability).

4. **EACH TIME you use part of the toolkit, you should give feedback to the V&S researchers** as soon as possible. You need to do this by filling in an online questionnaire (with tick-boxes and space to write about your experiences and ideas. We think each feedback session will take about 15-30 minutes. It is OK to say that you don't want to answer a particular question.

5. Do I have to take part?

No, **the decision to take part is completely up to you**. You are free to change your mind and withdraw from the study at any time. If you have been sent the toolkit, you do not have to use it. You don't have to give a reason. However, any feedback forms you submit will be used in the study and cannot be withdrawn.

6. Are there any risks for me in taking part in the study?

The research topic is not an easy one. Thinking and talking about the end of life of people with learning disabilities, and planning ahead for this, can be upsetting or emotional. It may be particularly difficult if you are thinking about someone dying if they are close to you. If you find that things become too upsetting, you can stop or continue at a later time.

We provide guidance about how to manage and what to do if you find you are getting upset whilst testing the toolkit with someone you support, or with their family and friends.

If you would like extra support or advice, you can email the researcher who sent you the toolkit. They can either listen and talk with you some more by telephone, or they may suggest other professionals or support organisations that you can help you.

7. Are there any benefits for me in taking part in the study?

In our studies so far, we have found that many staff actually enjoyed talking about dying (and some were quite surprised by this).

As a benefit to being in the study, you will receive early access to the new toolkit, including guidance on supporting end of life decision making with people with a learning disabilities. There are also benefits to the people that you support as you will learn more about how to use an end-of-life care planning resource that was co-designed by people with learning disabilities, family carers, and relevant professionals.

You may also enjoy knowing that you contribute to the development of an important resource.

8. Will my information be kept confidential and secure?

Yes, we will protect your privacy at all times. We comply with all the GDPR regulations. We have written down detailed steps about how we keep your information secure. This has been reviewed and approved by an ethics committee. Here are some of the steps taken to ensure confidentiality:

- All information and data will be uploaded immediately to the Kingston University secure system.
- Your personal data will be separated from your other information (and kept secure).
- When it comes to publishing the results of the study, we will tell the stories of the people who took part in the study, with quotes of what they said, but we will use pseudonyms and change any details that might identify you.
- On the feedback form, we ask you NOT to mention any names or identifying details of anyone involved in testing the toolkit.

Everything you tell us in this research is confidential. However, if we are told something that gives us reason to be concerned that someone may be at risk of harm, we have a duty to tell someone. This could mean informing the police, social services or other relevant organisations. We would discuss this with you before telling anyone else anything you have told us.

9. Who has approved the study?

Research of this kind is reviewed by an independent group of people, called a Research Ethics Committee which is here to protect your safety, rights, wellbeing and dignity. This study has been reviewed and was given a favourable review by the Social Care Research Ethics Committee (reference 23/IEC08/0033).

10. Who is funding the study?

The study is funded by the National Institute for Health and Care Research (NIHR) Research for Social Benefit Programme (study number: NIHR202963)

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11. Who do I contact if I have any concerns or complaints?

If you have any concerns or complaints about anything to do with the **Victoria & Stuart** Project, you can contact and talk with the researcher who has sent you the link to the toolkit.

If you prefer to talk with someone else (or more senior), you can telephone or email **Professor Irene Tuffrey-Wijne**, who is in charge of the study:

Email: I.Tuffrey-Wijne@kingston.ac.uk

Address: Kingston Hill Campus, Kingston Hill, Kingston upon Thames, Surrey, KT2 7LB

Please note that post may not be picked up regularly