

About this guide

This guided conversation tool aims to help you talk with people who are approaching the end of their lives and are thinking about preparing for their final goodbyes. It can also be used to help those facing the death of someone close to them, no matter how far ahead or uncertain this may be.

At the end of the booklet is a section of Additional Information which contains some helpful definitions and further sources of support and information. You can select and offer these to the person you're talking to depending on their circumstances and any practical actions you or they may decide to take. We suggest you read through this so that you have an idea of what is there before beginning your conversation.

A guided conversation means that you allow the conversation to unfold in whatever way the person you are speaking with needs to. This booklet provides prompts and reminders of things you may want to try to cover, to help you find your way through what may be a painful, sensitive and difficult subject. You may also want to use the booklet to record key things that have been shared and for your own personal support process – there are note pages provided at the end of this document for this purpose.

Be aware that the person you are speaking with may tire easily or have limited energy levels and it may be that they need more than one call or face to face meeting to complete the conversation. Be sensitive to this and to the impact that the conversation is having on them.

Please note that this guide is intended for use by staff, volunteers and people working within an organisation providing professional/befriending/chaplaincy support and who themselves have access to guidance, supervision and support. In using this guide you should also be aware of and abide by your organisations policies and guidelines on areas such as Data Protection, Confidentiality, Safeguarding Adults and the Mental Capacity Act.

Self care and self-awareness are paramount in having conversations with people who are approaching death. It is essential you have some awareness of what these issues may mean in your own life and that you have support in preparing for and debriefing after each call or face to face meeting. It is also important that you do not exceed the boundaries of your role and know who to contact for advice on any actions arising from the conversation.

Unconscious Bias

As human beings we all form biases, assumptions, opinions and stereotypes as part of making sense of our world. It is important to be aware of our own biases and stereotypes as they can unconsciously affect how we understand and engage with others.

When interacting with the people we are supporting we should try, as much as possible, to be aware of our own assumptions and biases, put them to one side and maintain an open mind. Each person we interact with is a unique individual with their own personal history, story, personality, knowledge and feelings and we are there to learn about them, from them.

Although personal feelings, experiences and perceptions are important when we interact with others and these form a valuable part of the relationship, it's also good practice to reflect on how they might influence our behaviour towards the people we are engaged with. It is also important to seek additional awareness about this through support and supervision sessions with our line manager.

A roadmap for your conversation

A suggested overall structure to keep in mind for your conversation is:

- 1. Introducing yourself and the subject.**
- 2. Checking in on their feelings and experience.**
- 3. Helping them identify anyone they need to speak to, what about, and how they might begin this.**
- 4. Helping them to prioritise what's most important for them in their life now.**
- 5. Closing the call or face to face meeting.**
- 6. After the conversation has finished – next steps for you.**

1. INTRODUCTIONS

Contacting someone who is contemplating or facing death can be daunting. Death is something that is universal and connects us all, but because our society does not engage with the subject openly very much, most of us feel some sense of fear or taboo around it. It's good to remember that what can help a person most is that you are willing to hear their thoughts, feelings and questions, not that you necessarily have answers to all of them. Creating a compassionate space for them to talk and showing you are willing to listen and explore these with them is what is important.

Start by introducing yourself and your role. Be clear about what you are able to offer and ask if now is a good time to talk. If it's not, let them know when you might be able to talk again.

"Are there things that are worrying you about your life now?"

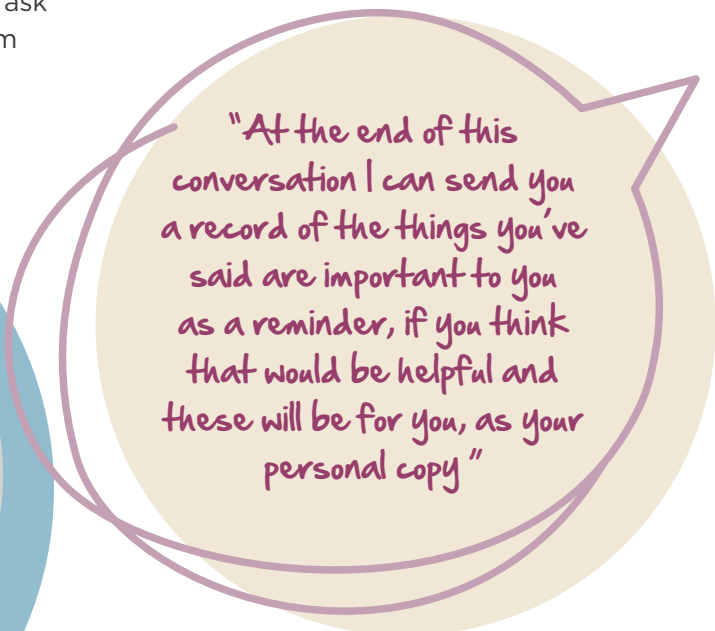
"What would you find it helpful to talk about with me today?"

"What do you feel you need/hope for today/from this conversation/at the moment?"

At some point during your introduction, let the person know that you can send them notes of the conversation afterwards if they wish.



Hello, my name is
***** and I'm from *****.
(say what has triggered the conversation, eg I was given your name by ***** who said there are some things you'd like to talk about) and I am making contact to see if I can be of any help at this time. Is this a good time for you to speak?

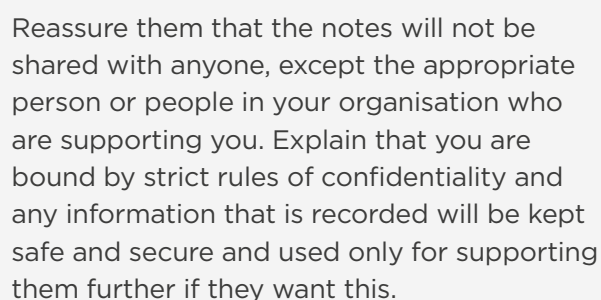


"At the end of this conversation I can send you a record of the things you've said are important to you as a reminder, if you think that would be helpful and these will be for you, as your personal copy"

A good place to start the conversation might be one or more of the following:

"Tell me about how things are for you at the moment"

"Tell me about how your day has been going today/how daily life is for you the moment"



Reassure them that the notes will not be shared with anyone, except the appropriate person or people in your organisation who are supporting you. Explain that you are bound by strict rules of confidentiality and any information that is recorded will be kept safe and secure and used only for supporting them further if they want this.

2. FEELINGS AND EXPERIENCES ABOUT DYING

When someone starts talking about their thoughts and feelings connected to their own death or that of a loved one, it's good to help them understand and express the feelings they are experiencing.

Feelings might include fear, sadness, uncertainty, regret, frustration, confusion, feeling lost, anger, hope, joy, relief or a mixture.

It may be useful to follow up on anything that they express with a further question, such as those below. Remember you don't need to ask all these questions – they are just examples to give you some ideas, depending on the flow of the conversation:

"Tell me more about that?"

"When did you notice these feelings?"

"Have there been times when you felt like this before (when someone died/you experience a loss)?"

"Are there times when you feel differently?"

"What helps you?"

"How have you coped with those /difficult feelings in the past?"

"What is important to you at the moment?"

"What would help to give you hope/joy/peace?"

3. TALKING WITH OTHERS

As someone nears the end of their life, there may be many things they wish to discuss with those who are important to them, or with someone who can be there for them at this important time. However it can be very difficult to know how to approach these conversations, particularly because our society does not openly engage with death and dying very much. It can be beneficial to help the person explore if there are any things they want to say and who they want to say these things to, as a natural way of preparing for their death.

Some things to be discussed may be **practical** – making sure that others are aware of their wishes with regard to how and where they spend the rest of their lives; and when they do eventually die, their funeral preferences and how their possessions will be distributed. Conversations about where they would like to die might also be helpful. Although the dying person might want to be at home, in reality this isn't always possible.

For example; if their level of care needs increase or if pain cannot be managed successfully in the home environment. So, having an open and transparent conversation about this subject will help them to consider every possible eventuality. In addition, it could help to minimise any feelings of guilt felt by the care giver if the dying persons wishes cannot be carried out.

Other needs are **emotional** – letting someone know how much they have meant to them, or resolving an old misunderstanding; or simply acknowledging to someone close that they will soon die.

There may also be a desire for conversations about the **spiritual** – their soul needs – finding inner peace for example.



3A. OTHERS COPING WITH ANTICIPATED LOSS

When people are nearing the end of their lives, loved ones and other third parties are also having to cope with anticipated loss and the reality of mortality. There may be conflicting feelings, unspoken difficulties, tensions, or differences of opinion. Everyone engages with the subject of death and dying differently and each person's encounter with the reality of bereavement is not only individual and unique to them, but also to their relationship to the person who is dying. So it is important to remember that your primary responsibility is towards the person you are supporting, responding to what they feel and need and that it is a matter between you and them.

Things can get rather complicated if you find yourself trying to talk both to the person you are supporting and to others present who have vested interest in the conversation, with their own feelings and opinions about matters. Of course, it's also important to be respectful and sensitive to any feelings or

needs that might present and not to display a protective, suspicious or defensive position. We cannot judge the nature of other peoples' relationships, they are almost always complex and have many hidden dimensions we may not be aware of.

So in general, unless, the person you are supporting has expressed a clear wish to have that person with them*, it might be better to suggest diplomatically that you can visit them again another time.

**if you know in advance that the person you are supporting wishes others to be present when you visit, then it's a good idea to first understand something about their role in the life of the dying person, as well as get support for yourself in planning the meeting. In addition, setting out some simple boundaries and expectations about each persons role before the meeting takes place might be helpful.*



3B. HOW TO START A CONVERSATION

The prompts in this section are intended to help you sensitively probe and ask questions. You will need to use your judgement and avoid overwhelming someone with possibilities – but be ready to go there if they are.

If there are things you feel unsure about, or you start to feel out of your depth, it's good to let the person know that you have heard the important things they are saying or asking – and that although you are not sure what the answer is, you will be able to talk to someone in your organisation who may be able to help.

You may find it helpful to familiarise yourself with the examples listed on the following pages, under the headings of Practical, Emotional and Spiritual. Then begin with an opening question such as:

"Is there someone in particular you would like to speak to about your needs, hopes and wishes at this stage of your life?"

(This could include close relatives or friends, or a professional – a spiritual guide/chaplain, counsellor, or solicitor).

You might then enquire:

"What kind of thing would you like to speak with about?"

People often find it difficult to address these topics with those close to them, so it can be helpful to help them think through **how** they might begin the conversation.

"Have you thought about how you would start that conversation with your daughter /husband/neighbour/friend?"

Summarising what they have told you is a good way to let them know that you have heard and understood what they have said, and can encourage the person's thinking.

"Let me just check with you that I have understood what you have told me. You would really like to speak with X about Y, and you would also like to talk about your will but you are not sure who is the best person to talk with, is that correct?"



3C. EMOTIONAL THINGS PEOPLE MAY WISH TO DISCUSS

There can often be a desire to address things in the person's relationships, past or present, which have remained unspoken or unaddressed until now. Here are some ways to open up and explore this area:

- Are there things you need/want to communicate to others before you die?
- Who are those people you most want to communicate with?
- What would you like them to know?

You could use the following kinds of questions to explore further:

"When you think of those you may leave behind, is there something that concerns you, that needs to be said?"

"Who in your life is it important for you to communicate these things to?"

"Is there something that you would like them to know, perhaps to resolve a misunderstanding or simply to express appreciation, forgiveness or regrets?"

"Maybe you would like to be able to recall memories you have shared?"

Use this space to write down the names of people they would like to say more to and something they would like to say to them. If those people are no longer alive, or they cannot speak to them, then they may like to share these thoughts just with you, with a chaplain, counsellor or someone else.

It may be that the person will not be able to communicate directly with someone important to them and they may seek help with writing a letter or having a message passed on after their death. You may need to check your organisation's policy and approach to this before making any commitments.

3D. SPIRITUAL THINGS PEOPLE MAY WISH TO DISCUSS

Living in a society represented by many cultures and religious views means it is important to be aware that the person you are working with may have particular religious beliefs surrounding death and dying. There may be cultural practices that are important to them or their family and there may be particular funeral and burial rituals that they need to be observed. You do not need to be an expert in these things. The important thing is to ask, be respectful and curious about what and who is important to them, in terms of their culture and background and reflect back to make sure you have understood.

As people approach the end of their lives, spiritual questions may come to the fore, whether or not they have a particular religion or faith. They may for example be wondering

- **What will happen to me after I die?**
- **What does my soul need now?**
- **How can I feel more peaceful about my death?**

These questions may be difficult for them to express and hard for you to respond to. Remember, your role is not to provide all the answers as these will also depend on any spiritual beliefs that they hold. What matters is that you hear how important those questions are, help them express their thoughts and feelings around the questions and identify if they would like to speak to someone in a spiritual capacity.

This might be for example a chaplain or member of the clergy, a Rabbi, Imam, Granthis, Swami or other faith/spiritual leader. It could also be a counsellor, or someone they know and trust.

Use the pages provided at the back of this document to record anything they tell you about their worries, thoughts and wishes.

You might also want research the meaning of a specific faith or religious ritual or protocol once the call or face to face meeting has ended. For example the ['List of Religious Titles and Styles'](#) via Wikipedia.

3E. PRACTICAL THINGS PEOPLE MAY WISH TO DISCUSS

Here are some examples of practical issues people may wish to talk about. This list is here to help you prepare, you do NOT need to ask about all of these points. Always be guided by what the person wishes to discuss and avoid questioning them too much if you sense they just want to focus on one thing, or are tired.

- **Any preferences about where they are cared for and to be when they die.**
- **Registering a Lasting Power of Attorney so someone they trust can make important decisions for them, should they become too physically or mentally frail to do so.**
- **Who they would want to be informed and involved if they become ill and needed treatment and anyone they would not want informed or involved.**
- **Who they would like to look after any dependants and pets should they become unable to do so because of illness or when they die.**
- **To ensure that others are aware of any religious or cultural practices that need to be observed.**
- **What happens to their estate and possessions when they die – their Will (see [Additional Information](#)).**
- **What happens to their body when they die (e.g. Medical research, cremation, burial?).**
- **Their wishes for their funeral (see [Additional Information](#)).**
- **Things other people may need to know – keys, savings, diaries, mementos, computer passwords, etc.**

Use the pages provided at the back of this document for your notes about Practical things to talk about and **who** they want to discuss them with.

4. WHAT IS IMPORTANT IN MY LIFE NOW?

Before you conclude your conversation, you might invite the person to consider what they need while they are living and to encourage them to focus on what might be important in the here and now.

Like all the questions in this guide, this is a highly individual question which depends on the person's own situation and life journey. As in the previous section, someone's concerns for their present life may be practical, emotional or spiritual. Here are examples:

- Enjoying the time I have left
 - appreciating the life I have.
- Making peace with myself.
- Expressing something (gratitude, appreciation, disappointment, concerns) to someone.
- Getting my practical affairs in order
 - writing my will, etc.
- Putting other things in place for those I love.
- Being honest with those I am close to.
- Writing or talking about my experiences and life for the benefit of others (see also the section [Making a Memory Box](#) in [Additional Information](#)).
- Making sure **** will continue to do my cleaning and shopping/collect my medicines/walk the dog.

"We've talked a lot about dying, I wonder if you'd like to spend some time thinking about life for you at the moment and what's most important to you in the days to come?"

If there is something specific that is important to the person, check with them whether they need any help to achieve these.

"Who do you need to speak to? Care agency or private carer, neighbour, GP, family, chaplain?"

"Is there any practical help you would need to do this?"

People may sometimes have wishes which are unlikely to be achievable. The important thing is to acknowledge those wishes without making promises or raising expectations.

Use the pages provided at the back of this document to write down the things that the person feels are most important to their life now and any practical steps you or they need to take. You could also write down any information you want to send them after the conversation.

5. CLOSING THE CONVERSATION

Check if there is anything else the person wants to tell you. If they are tired you might suggest calling or visiting again if they would like you to.

People may sometimes express something important towards the end of the conversation, for example emotional or spiritual needs which were not mentioned earlier. The golden rule is to acknowledge and hear the importance of whatever is said and be ready to return to previous sections if it seems relevant and appropriate.

Summarise the actions **you** will take as a result of the conversation and let them know if/when they will hear from you.

Summarise the actions **they** have discussed taking, such as beginning a conversation with someone close to them.

Thank them for their time and acknowledge that this is a very important time for them and that it may have been very emotional for them. Ask what they can do today to take care of themselves.

6. AFTER YOU'VE TALKED

First – check in with yourself. You may have an emotional reaction or tiredness after this conversation and you may go on thinking about certain elements of it. It is a good idea to write down as much as you can, both to ensure that you capture any actions agreed and as a way of processing your experience. Identify if there is anyone you need to speak to, either for advice about further actions or for emotional support. Make sure what you have written down is kept safe and secure in line with your organisations policies.

If you have agreed to send a record of the conversation, check that you have captured anything important that the person wanted you to record and arrange for it to be sent to them. Keep a copy for your organisation's records as well.

If you are feeling troubled, either by the content of the conversation or by wondering if you have handled something correctly, make arrangements to speak with the appropriate person confidentially, as soon as possible.

Try to take some time out to have a walk, to be in nature, or whatever it is that you find most nurturing.

Remember, self care is not selfish! It is always important that you look after yourself when you are acting in a caring or supporting role.

Post contact checklist

- How I felt the call or visit went in general – was it helpful to the person?
- Actions I agreed to take
- People I need to contact



Additional Information

Planning Care in later life

There are a number of legal processes and documents that can help a person express their wishes and plan in advance the care and treatment they may need before they die, and who they wish to involve in this. This is especially important in case the person's illness makes them unable to communicate their wishes at a later point.

These include:

- [Advanced Care Plan](#)
- [Advanced decision to refuse treatment \(Living Will\)](#)
- [Advanced statement about your wishes](#)
- [Lasting Power of Attorney](#)
- [Recommended Summary Plan for Emergency Care and Treatment \(ReSPECT\)](#)

The person you are speaking with may already have these in place and may refer to them, or they may tell you something that indicates they wish to set something up. If they do so, you could ask them who they wish to discuss this with and subject to your organisation's policy, suggest that you arrange for someone to contact them (after you have consulted your manager, if necessary).

Writing or Changing a Will

If someone is asking about writing a will, the following information may be helpful to them. You should not raise the topic if they do not and you should avoid getting involved in discussing the content of a will. If someone asks for advice, a useful phrase may be:

*"I can't advise you on who you should leave *** to, but would encourage you to think about what will give you the greatest sense of comfort and peace."*

You can also explain the following information to them if they seem interested:

- A will gives clear instructions about what you want to happen to your money, property, possessions (known as your estate) and online accounts after you die. If you've already made a will, you may want to re-read it to make sure it reflects your current wishes.
- It's best to use a solicitor when making a will.
- More complete information and guidance can be obtained from Age UK or other charities. For example, Age UK has a simple Information Guide "Wills and estate planning"



Designing Their Funeral

You can help someone to think about their funeral, if they wish to, by referring to the information below.

Writing down their preferences can help those who will arrange their funeral to make sure that the funeral reflects them and their choices. Knowing people's wishes in advance will also help those who are planning the funeral to have confidence in their decision making when the time comes. It is therefore worth writing their wishes down – this can be part of their will or can be done separately and put in a safe place where others who they trust can find it.

These are some things to consider:

- **Their religious or spiritual beliefs, which may influence many of the questions below.**
- **Their body: Do they wish to support medical science, or donate their organs? Do they want their body to be buried or cremated?**
- **Type of coffin? Wood, bamboo, cardboard eco-coffin?**
- **Any particular funeral director or celebrant to lead the process?**
- **Readings and music? Are there poems, readings, hymns or music which mean a lot to them, which they would like to include in the funeral ceremony?**
- **Catering and wake or party?**
- **Finances: Of course many of these choices may influence the cost of the funeral. Funeral expenses can be deducted from their estate, unless they have a funeral plan to cover the expenses.**

More complete information and guidance can be obtained from Age UK or other charities.

Making a Memory Box (Treasure Chest, Time Capsule)

If the person expresses a wish to reflect on the events of their life, and/or to leave some personal mementos of their life to others, this is one idea which can be explored.

A memory box is any collection of special things belonging to them. It might include photos, some favourite music, letters, small objects that mean a lot to them, or a recorded message – video or audio. It doesn't have to be a physical box – it may be computer files and photographs stored on a USB stick. The important thing is that it gathers together important memories that have meant something to them.

Making a memory box can be a way to reflect on what has been important to them in their life and can also be a record for their loved ones or others in the future.

Creating a memory box can be a very rich emotional experience. They may find it helpful to have a relative, friend or someone from their church support them as they create it.

For some ideas about memory boxes and end of life letters, please see:

Living Well in the End Times by Joanna Colicutt, produced for the Diocese of Oxford: www.oxford.anglican.org/wp-content/uploads/2013/01/OD705-Living-well-book.pdf

Macmillan Cancer Care's website: www.macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/end-of-life/making-a-memory-box

FURTHER READING AND RESOURCES

Age UK have resources about death and dying. www.ageuk.org.uk/services/information-advice/guides-and-factsheets/guides-about-death-and-dying/

Starting the Conversation is a lovely graphic book by **Compassion in Dying**: www.compassionindying.org.uk/library/starting-the-conversation/

Conversations for Life: www.conversationsforlife.co.uk

End of life planning via Independent Age: www.independentage.org/get-advice/advice-guides-factsheets-leaflets/planning-for-end-of-life and practical ideas for difficult conversations about death and dying more generally: www.independentage.org/information/personal-life/difficult-conversations/practical-tips

End of life planning via My Future Care: www.myfuturecare.org

Independent Age www.independentage.org – contains useful articles on ‘Things to talk about before someone dies’ and ‘Talking about end of life planning’

Journeying Home by The Salvation Army: www.faithinlaterlife.org/wp-content/uploads/2019/01/Journeying-Home.pdf

Preparing to Say Goodbye guided conversations toolkit and/or training and workshops available upon request via www.tttb.org.uk / info@tttb.org.uk

Research opportunities. Henglien Lisa Chen, is a Lecturer in Social Work and Social Care at the University of Sussex. Lisa is interested in research relating to ageing and ageing care. Please contact her if anyone is interested in exploring research further: h.l.chen@sussex.ac.uk

ReSpec (Recommended Summary Plan for Emergency Care and Treatment) www.resus.org.uk/respect

Resources, fact sheets, guides and leaflets for older people through Independent Age: www.independentage.org/get-advice/advice-guides-factsheets-leaflets

Support for carers information via Dying Matters: www.dyingmatters.org/page/information-carers

Support for all kinds of grief: www.griefrecoverymethod.com

Support for those who would like to die at home but are alone: www.eol-doula.uk

The Good Grief Project podcasts, information, webinars, festival on demand: www.goodgrieffest.com

Time to Talk Befriending Resources www.tttb.org.uk/resources

BOOK SUGGESTIONS:

'We all know how this ends'
by Anna Lyons and Louise Winter.

‘A matter of death and life’
by Irvin and Marilyn Yalom.

'In the Midst of Life' by Jennifer Worth.

‘Languages of Loss’ by Sasha Bates.

'Thinking of You: a resource for the Spiritual Care of People with Dementia'
by Joanna Collicutt.

‘Being Mortal’ by Atul Gawande.

(We are leaving room for organisations to add their own lists of relevant organisations and information sources.)

Notes

Notes

Preparing To Say Goodbye **RECORD**

Name of staff member or volunteer	
Name (of person being supported)	Date of call or visit
General Notes	
Queries to follow up	Who with
1. Introductions checklist	
<ul style="list-style-type: none"> • Explained purpose of call or visit • Checked if this is good time • Explained confidentiality • Offered written record 	

2. How is s/he feeling?	
3a. Practical issues to explore	Who with
Actions	
3b. Personal contacts s/he would like to speak to	Topic if known
Actions	

3c. Spiritual/religious person to speak to	Topic if mentioned
Actions	
4. What is important now	
Support needed?	
5. Closing thoughts	

Next contact with person?
6. Post call or visit checklist
Actions I agreed to take
People I need to contact on behalf of the person
How I felt the call/visit went in general – was it helpful to the person?
My own needs:
Debrief with supervisor/mentor?
Self care actions

Please don't hesitate to contact us if you need any further help or advice.

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to Bea, Cathy
and Claire for
collaborating on
this resource.

Thanks also to Peter
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and former lead chaplain
at Sussex County
hospital for his input
which contributed
towards this work.



Dr Bea Gahagan CPsychol AFBPsS
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Cathy Warren MBACP (Accred.)
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See website www.engaging-with-ageing.net



Claire Godley
is a Time to Talk Befriending Trustee
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Created in partnership with
our in-house Anna Chaplains



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