



No Barriers Here **Facilitator Training** **2024 Resource Guide**



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The Mary Stevens Hospice developed *No Barriers Here* and piloted it during the COVID-19 pandemic, in co-production with Dudley Voices for Choice and people with learning disabilities. It uses arts-based methods for advance care planning with the aim of reaching individuals and communities who are underserved by palliative and end of life care, supporting people in a more inclusive way to better understand, think about and share what matters most at the end of life. The pilot demonstrated that *No Barriers Here* could be used in different settings and with other marginalised populations, and since then has developed through further phases.

The attributes of *No Barriers Here* are an essential tool in advance care planning, particularly with people who experience health, socio-economic, structural and systematic inequalities. It won Hospice UK Tackling Inequalities Award 2021, NHS Improvement Awards 'Improving through Co-production', The 3rd Sector Care Award 2023 Development and Innovation Award and finalist for the Learning Disability and Autism Awards 2021.

The facilitator training programme will support health and social care professionals to facilitate the *No Barriers Here* model and deliver the programme, making a positive and meaningful difference to tackling inequality in palliative and end of life care in the UK.

Acknowledgements

The co-founders and first *No Barriers Here* co-production team:

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No Barriers Here Background



A public health approach to palliative care

No Barriers Here uses a model that adopts a public health approach to palliative care, working alongside communities who experience systematic difference and inequality accessing palliative and end of life care and challenges the barriers that organisations and healthcare systems often create. *No Barriers Here* has been used and tested with many individuals and communities, including in hostels, children’s palliative care, dementia services and LGBTQ+ people. It is transferable across different settings and populations. Please see the below examples and visit our website for case studies, reports and resources.

No Barriers Here and people with learning disabilities

In the UK, there are more than 1.5 million people with a learning disability. Many experience health inequalities and are more likely to die at a younger age than the overall population. Despite advance care planning being an essential part of palliative care, health care professionals frequently avoid end of life conversations with people with learning disabilities. The Mary Stevens Hospice developed *No Barriers Here*, in co-production with Dudley Voices for Choice and people with learning disabilities in 2019, using arts-based methods for advance care planning and enabling a less verbal approach. The co-production team co-designed accessible information, videos, *No Barriers Here* workshops and co-delivered education to healthcare professionals. They have continued to work with *No Barriers Here* including co-authoring conference abstracts and an academic book chapter.



‘It’s more than rainbows in receptions’

This study came about from a reflection from an LGBTQ+ person who noticed an increasing tendency for organisations to make efforts to display the rainbow flag (or progress flag) as a sign of LGBTQ+ inclusivity, but without deeper thought, culture change, training, or improvements in care delivery. It formed the first provocation for the coproduction group to consider – how does real LGBTQ+ inclusive care happen beyond rainbows in receptions?

New resource coming 2024....

No Barriers Here and people excluded by identity, culture, ethnicity and race (ICER)

Recent research (Care Quality Commission 2016, Chidiac *et al.*, 2020) highlighted the continual presence of barriers in healthcare services and services not appropriately meeting the needs of people from minoritised ethnic communities. This is true of palliative care (Hussain, Koffman and Bajwah, 2021) and covid-19 highlighted further health inequalities and racial injustice (Chidiac *et al.*, 2020). *No Barriers Here* (ICER) is a co-produced, community-based, study that explored access to palliative and end of life care and advance care planning for people who may be excluded by identity, culture, ethnicity or race.



Illustration: Cass Humphries - Massey



No Barriers Here©

Advance care planning



Advance care planning

No Barriers Here offers an equity-oriented approach to advance care planning and planning ahead for future care. It enables people the opportunity to think about and discuss their choices and wishes for how they live their life and the end of life.

Often discussions about planning ahead happen once a person is referred to palliative care services or considered to be in the final 12 months of life. *No Barriers Here* proactively encourages early conversations with individuals and communities, particularly those who experience inequity and barriers accessing palliative and end of life care.

No Barriers Here enables a gentle introduction to advance care planning, encourages healthcare professionals to listen to the voices of those who are underserved and provides a more equitable and less verbal approach for people to think about their end-of-life care.

In the UK an advance care plan is not a legally binding document and can be amended at any time. It includes information about how people would like to be cared for at the end of life, preferred place of care and death, important people, values and wishes.

Early advance care planning ensures that if a person is unable to make their own decisions, family members, friends health care professionals or other people within their circle of support understand what matters most to them. *No Barriers Here* incorporates this information through the use of arts-based methods, exploring individual choices and decisions. We recommend having paper/ electronic advance care plans available if a person decides that they would like conversations from within the workshops documented.

Remember: *Advance care planning should never be seen as a tick box or form filling procedure. It is a series of conversations that takes place over time.*



"I found it very difficult at first, but as the weeks went on I found I was more comfortable planning for the end of my life."

Workshop participant



No Barriers Here Co-production and engagement



Working in co-production



Recognises individual skills and assets



Breaks down barriers and reduces inequalities



Develops existing abilities



Work together = achieve together

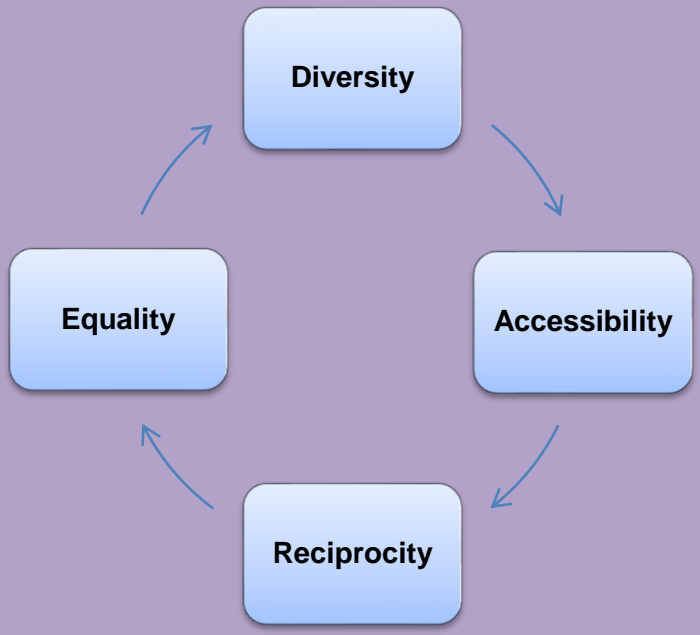


Organisations as change agents, not service providers

Consider who you want to engage with using *No Barriers Here*. Do you plan to work with a specific population who experience inequalities accessing palliative and end of life care services?

We highly recommend working in co-production with community members who will bring their own expertise and help to steer the project.

For example, if you plan to facilitate the workshops with people with learning disabilities you will need to consider making reasonable adjustments, using easy read materials, ensuring the space is accessible and allowing additional time during workshops. Nobody can inform this better than people with lived experience. Likewise, working with a Polish community may require an interpreter or written documents translated.



“A relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities.”

National Co-Production Critical Friends Group



No Barriers Here Communication 1



Introduction

Communication is defined as the process of exchanging thoughts or information between individuals. Every communication involves (at least) one sender, a message, and a recipient. This may sound simple, but communication is an extraordinarily complex subject. The transmission of the message from sender to recipient can be affected by a vast range of things. These include our emotions, the cultural situation, the medium used to communicate, and even our location. It is important to recognise barriers, from ourselves and others, that can inhibit communication. It is also necessary to understand the core skills that can be used to facilitate effective communication. Good face-to-face communication between health and social care professionals and patients and carers is fundamental to the provision of high-quality care.

What inhibits communication?

- The use of jargon and euphemisms. Over-complicated, unfamiliar and/or technical terms. Use clear and concise language.
- Giving premature or false reassurance.
- Normalising a person's fears e.g. *"I am scared of death" ... "Everyone feels frightened of dying."*
- Passing the buck.
- Switching the focus of the conversation e.g. *"I am worried about dying at home" ... "How does your partner feel about it?"*
- Emotional barriers and taboo subjects- some people may find it difficult to express their emotions and some topics may be completely 'off-limits' or taboo. These may include, but are not limited to religion, disabilities, sexuality, racism, and any opinion that may be seen as unpopular.
- Lack of attention, interest, distractions, or irrelevance to the receiver.
- Differences in perception and viewpoint.
- Sensory impairments such as hearing problems or speech difficulties.
- Physical barriers to non-verbal communication. Not being able to see the non-verbal cues, gestures, posture, and general body language can make communication less effective.
- Expectations and prejudices which may lead to false assumptions or stereotyping.
- Cultural differences. The concept or what is accepted as normal social interaction can vary in diverse cultures, as does the way in which emotions are expressed. For example, the concept of personal space varies between cultures and between different social settings.
- Language differences.
- Learning disability- people with a learning disability may communicate and express themselves differently. Know how they understand information, communicate and express themselves.

Barriers to communication

There are many barriers to communication, and these may occur at any stage in the communication process. Barriers may lead to your message becoming distorted and you therefore risk wasting both time, trust, and opportunities by causing confusion and misunderstanding.





No Barriers Here Communication 2



How do we communicate?

There are many ways of communicating and we may be doing more than one at any given time.

Spoken or Verbal Communication (*face-to-face, telephone, radio or television, podcast and other media*).

Non-Verbal Communication (*body language, gestures, facial expression, eye contact, how we dress or act, personal space, and even our scent*).

There are many subtle ways that we communicate with others. For example, the tone of our voice can give clues to mood or emotional state, whilst hand signals or gestures can add to a spoken message.

Written Communication (*letters, e-mails, social media, books, magazines, internet, and other media*).

What facilitates effective communication?

People are more likely to disclose their concerns to health and social care professionals who demonstrate that they are prepared to listen and open to discussion. There are several skills which facilitate effective communication.

| | | |
|------------------|-----------------|-----------------|
| Active listening | Silence | Acknowledgement |
| Encouragement | Picking up cues | Reflection |
| Clarification | Empathy | Challenge |

Resources and tools to support communication

Think about how communication can be supported to meet individual need. For people who do not speak English as a first language, translated written materials and an interpreter may be required.

People with a learning disability may need additional tools to support communication such as easy read, pictorial resources, art or electronic boards.

Sage & Thyme training
<http://www.sageandthymetraining.org.uk>

Note: A skilled communicator must be aware of the potential barriers to effective communication and try to reduce their impact by continually checking understanding and utilising these communication skills.

Ascertain the preferences of individuals and involving them in decisions about their health and wellbeing requires that those responsible for leading the discussing have effective communication skills.

“Be quick to listen and slow to speak”

James the Apostle



No Barriers Here

Using arts-based methods 1



Why art?

Art and art-making offer a different way of exploring and expressing thoughts, feelings and emotions, rather than talking and writing. Traditional approaches to advance care planning rely on verbal conversations based on questions that often prompt a focus on the answer, rather than an exploration of the question. Using art-making allows a less verbal way for participants to take part. It also allows multi-level exploration and expression of information which is often difficult in verbal conversation between professionals and patients or service users. You will experience this when we work through the workshops later in the course.

Legacy feelings about art-making

Many people have developed beliefs from their early education that they are 'not creative' or 'not good at art'. These beliefs are expressed often in these workshops. For this reason, it is important to focus on the process of making as much as the end product. These workshops are not about creating likenesses or realistic images. Rather, they are about exploring feelings, expressing preferences and symbolising important concepts. For example, a participant might say

'I want to draw the sea, but I am not good at drawing'

Rather than trying to persuade the participant that they are good at drawing, or feel pressured to teach the participant how to draw, the role of the facilitator is to help the participant think about how they might symbolise the sea.

'Ok, how might you represent the sea? Would some blue fabric or these papers work? Could you use the pastels to include some areas of blue which would represent the sea to you? Tell me more about the sea, why is it important? What do you remember about the sea...?'

The activities are designed to be accessible and to focus on symbolising and representing thoughts, feelings, priorities, preferences and memories.





No Barriers Here Using arts-based methods 2



Equity

Not everyone can communicate verbally. This might be for many reasons including language barriers and communication difficulties relating to disabilities and illness. However, there is a growing understanding that for many people who can communicate verbally on one level, connecting with deeper feelings and exploring them verbally is difficult.

For people who have experienced trauma, less verbal approaches have been found to be useful in regulating emotions and feelings such as panic, anxiety and dissociation. Art-making has a universality which is useful in these workshops. Although different cultures and communities might have different forms of the arts, the role of the arts across humanity is central.

TOP TIPS

Work alongside participants and create something yourself or have previously worked examples to hand.

Try to make sure these are of different styles and showing different qualities.

Encourage everyone in the room to take part. Try and avoid non-participant observers being present.

Take time to introduce the art materials and make suggestions about how they can be used.

Encourage people to add their own collage materials or bring things along for Week 2 and 3 if they want to. Remind them to only use copies of images/photos etc.

Keep comments about the quality of images out of discussions – brief co-facilitators to avoid comments such as ‘that’s really good’ or ‘I wish I could draw like that’.

Instead, focus on the feelings, thoughts, beliefs and memoires which arise in the image-making.





No Barriers Here Distress



What if participants become distressed?

Talking about death, dying and our wishes for the end of our lives can be distressing. It is important to remember to allow space for normal emotions to arise – fear, sadness, anger are all normal responses to these discussions.

No Barriers Here workshops are often characterised by sadness but also humour and joy. As facilitators, it is important to remember that both patient/service user participants, as well as staff members, may become upset. Death and dying are universal and often discussions about the end of our lives are great levellers between us all.



Things to consider:

Are you aware of appropriate agencies or services where additional support can be accessed by participants?

Are your participants particularly vulnerable? If so, are there other professionals you may need to communicate with about the participation in the workshops?

How comfortable are you, as a facilitator, in sitting with distress? Do you need extra support or expertise? If so, who might you co-facilitate with?

Use the art-making to express and contain the feelings which arise. Sometimes these workshops are the first time that some participants have explored or expressed these feelings and thoughts about their end of life.

Allow time at the end of the session for participants to share their experiences of the workshop and reflect on the process and items they have made. Include time after the session for anyone particularly upset to de-brief with the facilitators. Include support staff in attendance in this offer.



No Barriers Here

Consent and capacity



Taking consent

It is good practice to take consent from participants to take part in the workshops. It is important that participants understand the nature of the workshops they are taking part in, how the things they say and the images/objects they make will be stored, shared and returned to them at the end of the sessions.

There are many different factors you may need to take into account depending on the group you are working with. For example, in the first phase of *No Barriers Here*, we developed easy-read versions of the consent form. We also took verbal and video consent at the start of the online workshops and verbal consent at the start of face-to-face workshops.

Verbal Consent:

Explain what the participant is consenting to, for example: a) take part in the workshops b) be interviewed for evaluation purposes c) to have photos of their images/objects taken for education or publicity purposes.

You can adapt the consent form to suit your own particular setting.

Written Consent:

Prepare a simple consent form in advance. Provide enough time for each participant to read and consider the consent form. Ask for permission for each part so people have the option to consent to take part, but not have their images shared for example.

Video Consent:

If you have a group where signing a form is difficult, or where a video consent might be more appropriate, explain to the group that you will film consent. Ensure the filmed consent is stored securely on a backed-up secure hard drive.

Informed Consent:

It is helpful to prepare a short information sheet for participants to read in advance of the workshops and in advance of taking consent to participate. Consider accessibility of the information sheet depending on your intended participant group.



No Barriers Here: Improving Advance Care Planning for People excluded by identity, culture, ethnicity or race using arts-based methods and public health approaches to palliative care

Participant Information



Mental Capacity

It is important that participants have capacity to consent to participate, to understand the nature of the project and its aims. If you are working with a group where participants may have fluctuating capacity or where capacity is unclear, consider discussing with other professionals working with the person, or close family member where appropriate, to establish that the person does have capacity to take part and give consent at the time of the workshops.





No Barriers Here Planning your workshops



Resources

The following resources are required to facilitate *No Barriers Here* advance care planning workshops. All arts-based methods used in the workshops can be adapted dependent on budget and ability. You will need:

- A4 card
- Pencil
- Coloured pencils
- Oil pastels
- Fabric pens
- Glue
- Scissors
- Fat quarter (square of cotton)
- Loom board or weaving frame
- Fabric remnants
- Ribbon
- Wool
- Tags
- Felt squares
- Small brown bags
- A *No Barriers Here* labelled box or bag

Optional-newspaper/magazine cuttings, shells, pressed flowers, buttons, raffia coloured paper, collage card and paper, fibre mesh squares, sequins, collage materials.

Note: Participants will find it easier if materials are separated into labelled week 1, 2 and 3 bags for each workshop.

Resources can be purchased from www.dryadeducation.co.uk or other art suppliers. Each filled bag costs approximately £25 and these are for the participants to keep. Allow time for delivery and to create the bags. It is time consuming and if you are working in co-production, this is something that can be done together.

Face to face workshops

Consider your venue carefully. Dependant on the number of participants, it works best to sit around one large table, with room to access art boxes and work. *No Barriers Here* works best in small groups of 4 -8 people but can equally be delivered one to one or in slightly larger groups. Always use a co-facilitator for group workshops.



Online workshops

Resources will need to be delivered in advance prior to the workshops. One advantage of delivering online is that you can include people from across the UK.

Be clear about what online platform will be used and offer instructions and support to access it. Ensure participants have equipment to access the workshops such as a tablet or computer and adequate WIFI. Allow additional time at the beginning of each workshop for troubleshooting and to ensure that everyone is online.

Note: Consider and ask if participants require support with the workshops i.e. a carer/ support worker, interpreter etc.





No Barriers Here Facilitator requirements



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What do you need to facilitate *No Barriers Here* workshop programme?

- Two trained *No Barriers Here* facilitators are required to deliver a series of workshops. Please note, this is not a train the trainer programme so please do not train other members of your team.
- To understand the rationale of using art-based methods in palliative and end of life care.
- To understand the principles and concept of *No Barriers Here* and the role of it in regards to advance care planning and inequalities.
- To understand the core elements of each workshop with the knowledge and confidence to deliver to a group of people.
- The co-facilitator is required to support the lead facilitator to deliver and evaluate the programme.
- Both facilitators experienced and trained in advance communication skills.
- A sound knowledge, confidence and experience in advance care planning and planning ahead conversations.
- Confidence and experience in delivering workshops, training or education.
- Prototype box/ bag of art materials and completed art-based tasks to share.
- Art materials for participants.
- Consent forms for photography/ filming.
- Evaluation tool.
- Time - each workshop lasts around 1.5 hours, and you will need preparation time beforehand.
- Reflection - For many people attending *No Barriers Here* is the first time that they have thought about planning for the end of life. At the end of each workshop, allow time to reflect and for participants to discuss any concerns privately.
- You may consider involving someone with lived experience to help support and/or co-facilitate the workshops.

Grant funding - top tips!

The initial pilot of *No Barriers Here* and subsequent phases are a direct result of successful charitable grant funding and commissioned programmes.

- Read the grant guidelines and have your basic information ready.
- Consider the aims and activities of *No Barriers Here* - how does this align with the national ambitions for palliative and end of life care and your organisational strategy?
- Look for funding relevant to underserved populations, palliative care, art and communities.
- Work and apply in collaboration with system wide partners, including community organisations and people with lived experience.
- Speak with your Integrated Care Board about any available local funding or workstreams.



No Barriers Here Workshop 1 Getting to know me and what is important to me



- Resources**
- A4 card
 - Writing and drawing materials
 - Glue
 - Scissors
 - Collage materials e.g. paper leaves, mixed paper and card, magazine cuttings, pressed flowers, buttons, sequins etc
 - Hand template

What is the aim of the first workshop?

The first workshop enables people to start thinking about what makes their life meaningful. This may be thinking around identity, hobbies and values.

At the start of the workshop

Allow time for introductions and give the participants a brief overview of the programme. Each person will have their own art box or bag so invite them to familiarise themselves with the contents.



Workshop 1 guide

Start the session with introductions followed by the facilitator giving a brief overview of *No Barriers Here*. You can show a viewing of one of our films, but we advise against using PowerPoint slides - instead keep it human, authentic and non-intimidating, it's not a teaching session! Ask participants what they know about advance care planning before giving a summary on what it is and why it is important to think about planning ahead. It may be useful to have a blank copy of an advance care plan to share.

Explain how the *No Barriers Here* model enables people to think about advance care planning and the importance of early discussions but that it uses arts-based methods for a creative advance care plan. *Note: people do not need to be artistic or creative to facilitate or participate in the workshops!*

Invite people to open and familiarise themselves with their art boxes and demonstrate what contents are required for workshop 1. Using the A4 card ask the group to draw around their own hand. *Note: have some hand templates available for people who are unable to do this or encourage people to help one another to do this.*

Ask people to think about what gives their life meaning, their identity and values and invite them to draw, collage or symbolise what this looks like using the materials provided on or around their handprint. Encourage use of whatever drawing/collage materials people feel most comfortable using. Allow around 45 minutes for people to work on this, allowing for natural discussion and curiosity throughout. Before the end invite people to share their work and thoughts with the group. It is worthwhile facilitators having an example of their own to share. Ask everyone to reflect on how they found the workshop and give a brief description of what will happen at the next one. *Note: Not everyone will complete their artwork during the session and will continue it at home. Encourage them to discuss the workshop and share artwork with family or friends.*



No Barriers Here

Workshop 2

Choices and wishes



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Resources

- A fat quarter (material)
- Fabric pens/ oil pastels
- Glue
- Scissors
- Mesh, felt and fabric remnants

What is the aim of the second workshop?

The second *No Barriers Here* workshop builds on from week one and aims to explore people's choices and wishes for the end of life and after death. During this workshop people will think about what matters to them at the end of life, who is important to them, who would they want to make decisions on their behalf and who is in their circle of support. Preferred place of care and preferred place of death is discussed and wishes for after death. This workshop symbolises the importance of having everyday conversations about death and dying and advance care planning. The artwork from this week is suggested to be a community collaboration, sharing choices and wishes with others and exhibiting a joint piece of artwork such as a quilt.



Step by step guide

Divide the fat quarter into four squares, you can use fabric pens, oil pastels or strips of material and glue. Guide participants through one square at a time, allowing time to work on each square.

Square 1 - Explore who the significant people are in participants lives, who is important and who would they want involved in decisions about their care?

Square 2 - Where is important to the person, where is a preferred place of care and preferred place of death? Note that this may not be a building but the environment, feelings or personal items around the person

Square 3 - Ask what three things matter most at the end of life. What would people really want to be considered by health and social care professionals? What would they want family members, friends and other significant people to know?

Square 4 - Finally, encourage people to explore their wishes at death and following death. Things to think about include procedures, cultural considerations that need to be followed, organ donation and funerals.



Encourage participants to discuss the workshop with family and friends. Have copies of advance care plans available for people who would like to document the information from their artwork. Advise them to share this with their GP.



No Barriers Here Workshop 3 My Legacy



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What resources do I need?

- A loom (weaving frame)
- Wool, strips of fabric, ribbon, raffia etc.
- Scissors
- Luggage tags
- Felt pens
- A2 card

Alternative weaving suggestions you could use- cardboard templates, coloured paper cut into strips, wicker.



What is the aim of the third workshop?

The third and final workshop reflects on the information gathered in the first two workshops and focuses on personal legacies and how people want to be remembered. It allows time for people to consider their personal legacy.

How do they want to be remembered?

What are their personal attributes and how does this contribute to who they are as a person?

To think about a meaningful legacy, we need to look at how we live our lives, our personal history and what really matters most to us as human beings. Everyone has something to give, and this workshop enables the opportunity to explore what makes us unique and personal achievements. It is about valuing personal stories, humanity and meaning to peoples lived experiences.

Weaving was specifically chosen for this workshop as weaving is as old as time itself. Traditionally, ancient weaving was used to hear the stories of silenced women who used the finished product to make their voices heard through storytelling. There are also many connections to cultural traditions.



Step by step guide

Due to time constraints within the workshops, string the loom up beforehand with wool. Have a selection of different wool colours, ribbons and threads available with an example loom board to demonstrate to participants how to weave in and out.

Ask people to think about their personal attributes and values and to write three down on the card. Then invite participants to choose thread or ribbon to weave through the loom to reflect this. Some people may want to write the colours and what they symbolise on the card, before repeating on a tag to attach to the thread or weaving frame. Encourage discussion around the contributions of each person, particularly if workshop participants know each other. Pause the workshop after around 45 minutes to reflect as a group and sharing how people would like to be remembered after they have died. Allow reflective time at the end of this workshop for people to evaluate and reflect on the *No Barriers Here* workshops.



No Barriers Here Next Steps



Community of Practice

Congratulations you are now a trained No Barriers Here Facilitator! You will be automatically registered to the *No Barriers Here* Community of Practice. This includes meeting twice a year online with other trained facilitators and access to a protected facilitator area on our website, where you can access information, download our logo, read and submit case studies and participate in an online forum. Please do not share this password with others who have not completed the training,

www.nobarriershere.org

Password: NBHCOP22

You have completed the Facilitator Training: What next?

- Think about who you want to run the workshops with. If you are planning to work with a community who experiences inequity think about how the voices of people with lived experience can be included from the planning phase. Why have you chosen this group? What will the benefit to the group be and what do you hope to learn from them?
- You will receive the resources to deliver your first workshops between 2-6 weeks following the training.
- You must use the *No Barriers Here* name and logo on any advertising material or presentations and acknowledge/ reference *No Barriers Here* in media posts and press releases.
- This is not a train the trainer programme, therefore you are unable to train others in *No Barriers Here*.



“Such an amazing day. What a brilliant art-based approach to encourage people to have conversations about the end of life. Cannot wait to use this in practice!”

“The attention to detail and preparation was amazing. Feels comprehensive, resource orientated and nurturing.”

