

# Margaret's story



## Facilitation and resource pack

**NHS**  
Northumberland,  
Tyne and Wear  
NHS Foundation Trust

**NHS**  
South Tyneside and Sunderland  
NHS Foundation Trust

  
**St. Benedict's Hospice**  
& Centre for Specialist  
Palliative Care

**MACMILLAN**  
CANCER SUPPORT

North East and Cumbria  
**learning**  
**disability**  
network

## **Introduction**

Margaret's story is produced with the permission of Margaret Thornton, and support from the North East and Cumbria Learning Disability Network, St Benedict's Hospice and the Sunderland Community Learning Disability team.

At the point of making the film Margaret is palliative, she agreed to share her story to help others learn from the journey she has taken.

We are immensely grateful to Margaret for sharing her story and giving us the opportunity to stop and think about how we can better support and work with people with a learning disability and what good quality care looks like.

## **Aims of Margaret's story**

The film and resource pack aim to provide an opportunity for facilitated discussion, increasing awareness of the additional support and care an individual may need. The story-based learning allows people to think about their individual roles within health, social care or the third sector; how and when they offer support to individuals, and what good quality care looks like.

## **Who is this resource for?**

This film and facilitator pack is aimed at people working within: primary and secondary care, social care and third sector organisations who support individuals with a learning disability on disease pathways.

## **Access to the film**

Margaret's story is available on the Northern Cancer Alliance website at:

<http://www.northerncanceralliance.nhs.uk/resources-cancer-academy/supporting-people-with-palliative-care-needs/>

And through the You Tube links:

The full-length version of Margaret's story (approximately 11 minutes)

<https://www.youtube.com/watch?v=q9CTAW2RROY&feature=youtu.be>

The short version of Margaret's story (approximately 7 minutes)

<https://www.youtube.com/watch?v=2e35oJ1EGMU&feature=youtu.be>

The film can be viewed independently or as part of a planned education/awareness session using the session plan in this facilitation and resource pack.

There are two versions of Margaret's story. We recommend the long version. This is 11 minutes. A short version is also available at 7 minutes.

## **How to use Margaret's story**

Margaret's story can be used as a short film watched independently, but for a greater impact we would recommend presenting as part of a facilitated group discussion.

If you watch Margaret's story independently, we ask you to think about the learning points highlighted below and how you could improve the journey for people like Margaret.

If you are use Margaret's story as part of a facilitated group learning session, we have included a suggested session plan and slide deck.

## **Learning Points for those watching Margaret's story independently**

Please take time to think about the following learning points after you have watched Margaret's story.

### **1. Communication**

Margaret repeats that she felt unheard. What reasons might have contributed to this?

Please consider:

- Margaret was not flagged on any primary or secondary healthcare system as having a learning disability, what difference did this make to her care?
- When you share complex information with individuals how do you ensure they understand the information?
- How do you ensure diagnostic overshadowing (where symptoms are overlooked) does not occur for people with communication challenges?

### **2. What does good quality care look like**



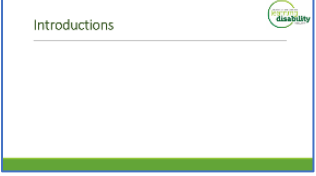
Margaret was very satisfied with her care once linked with the learning disability team. What do you think made the difference?

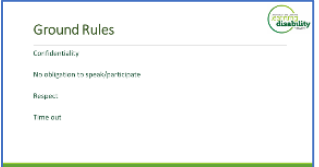
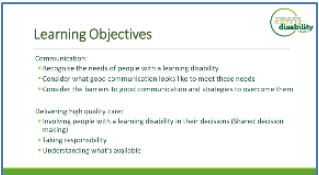
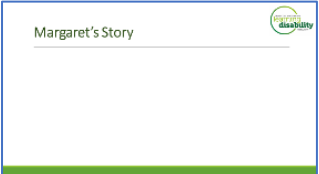
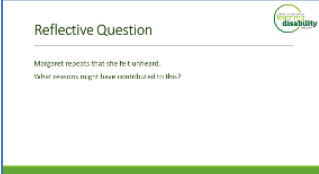

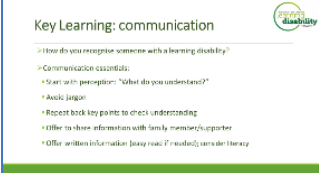

Please consider:

- If you are aware of a person you think may have a learning disability and would benefit from additional support, what can you do?
- When you next meet a person like Margaret, what can you do, within your organisation or role to ensure they are receiving the best possible care and support.

## Margaret's story – Example session plan

Time	Suggestion of 1 hour 30 minutes for the session
Resources	Ability to play film with sound
Group size	To enable good discussion, suggest a group between 6 and 12. If you are working with a larger group have additional facilitators to support discussion.
Room layout	Ensure the room layout enables discussion
Safe environment	Ensure you create an environment that feels safe and allows people to discuss Margaret's story. This is about learning and not placing blame on any individual/s or organisation/s. You may feel it is beneficial to have a break out room in case any individual wishes to take time away from the discussions. Also remind individuals to not share patient identifiable information within any discussions.

	Approx. timing	Aim	Detail
 <p>Margaret's Story</p>	0.00 – 0.15	Opening slide	<p><i>“Margaret’s story is produced with the permission of Margaret Thornton, and support from the North East and Cumbria Learning Disability Network, St Benedict’s Hospice and the Sunderland Community Learning Disability team.</i></p> <p><i>At the point of making the film Margaret is palliative, she agreed to share her story to help others learn from the journey she has taken.</i></p> <p><i>We are immensely grateful to Margaret for sharing her story and giving us the opportunity to stop and think about how we can better support and work with people with a learning disability and what good quality care looks like.”</i></p>
 <p>Session structure</p> <ul style="list-style-type: none"> <li>Introductions &amp; ground rules</li> <li>Story</li> <li>Reflection questions: small group first</li> <li>Facilitated discussion: full group</li> <li>Highlight learning</li> </ul>		Session plan	<p><i>“Today we will be covering:...”</i></p>
 <p>Introductions</p>		Introductions	Introduce self to group. If group do not know each other facilitate introductions.

 <p>Ground Rules</p> <p>Confidentiality</p> <p>No obligations to speak/participate</p> <p>Respect:</p> <p>Time out</p>		Ground rules	These can be added to by the group through discussion.
 <p>Learning Objectives</p> <p>Communication:</p> <ul style="list-style-type: none"> <li>Recognise the needs of people with a learning disability</li> <li>Consider what good communication looks like to meet those needs</li> <li>Consider the barriers to good communication and strategies to overcome them</li> </ul> <p>Delivering high quality care:</p> <ul style="list-style-type: none"> <li>Involving people with a learning disability in their decisions (Shared decision making)</li> <li>Taking responsibility</li> <li>Understanding what's available</li> </ul>		Learning objectives	Read through with the group. Does anyone want to get anything else out of the session?
 <p>Margaret's Story</p>	0.15 - 0.30	Margaret's story	<p>Possible text:</p> <p><i>"This session uses Margaret's story to help us think about how we support people with a learning disability and in this case a terminal cancer diagnosis. Margaret's story talks about her cancer journey, I will be showing Margaret's story on the screen and ask you to think about how her experiences relate to your roles. Please note this session is about learning from Margaret's story and not apportioning blame."</i></p> <p>The full length version of Margaret's story (approximately 11 minutes)  <a href="https://www.youtube.com/watch?v=q9CTAW2RR0Y&amp;feature=youtu.be">https://www.youtube.com/watch?v=q9CTAW2RR0Y&amp;feature=youtu.be</a></p> <p>The short version of Margaret's story (approximately 7 minutes)  <a href="https://www.youtube.com/watch?v=2e35oJ1EGMU&amp;feature=youtu.be">https://www.youtube.com/watch?v=2e35oJ1EGMU&amp;feature=youtu.be</a></p>
 <p>Reflective Question</p> <p>Margaret reports that she felt unheard. What reasons might have contributed to this?</p>	0.30 - 0.35	Reflective qu. 1	Ask group to discuss in small groups of 3 – 5 people
 <p>Margaret felt unheard</p> <p>"She wasn't recognised as needing more clearly considered communication"</p> <p>She didn't understand what she was being told</p>	0.35 - 0.50		Following discussion, discuss points
 <p>Key Learning: communication</p> <ul style="list-style-type: none"> <li>How do you recognise someone with a learning disability?</li> <li>Communication barriers</li> <li>Start with perceptions: "What do you understand?"</li> <li>Audio/visual</li> <li>Repeat back key points to check understanding</li> <li>Offer to share information with family member/supporter</li> <li>Offer written information (easy read / translated) via the library</li> </ul>			Highlight key learning points for communication. Would the group add any additional points
 <p>What makes communication difficult?</p> <ul style="list-style-type: none"> <li>Lack of continuity</li> <li>Lack of information (or inaccurate information)</li> <li>Lack of privacy/interruptions</li> <li>The nature of the discussion e.g. intimate, bad news</li> <li>Difficulty engaging the patient, e.g. cognitive impairment, hearing difficulty</li> <li>Strong emotions, e.g. anger, distress</li> <li>Experience/confidence of professional</li> <li>Dynamics between professionals, teams, services</li> <li>Time pressure</li> </ul>			Recognition of difficulty. Discuss with group some of the things that make communication difficult and how we overcome these, if these have not been covered.

<p><b>Communication Tips</b></p> <p>Communication is a <b>process</b> not an event</p> <p>Words are just a part of communication; think about the effect of eye contact, how and where you sit, silence, touch.</p> <p>If you don't have time, find someone who does - palliative care team, specialist learning disability team, flag with primary care team.</p>			Briefly discuss with the group
<p><b>Communication Tips</b></p> <p>THINK: right person, right time, right place?</p> <p>CHECK: do I have all the information I need?</p> <p>CHANGE: do you or the patient need someone with you? Can you prevent interruptions?</p> <p>ASK: questions: be sure to understand the patient's perception at the outset. Engage family/friends/other staff if appropriate and with permission; what is the person like when they're not a patient?</p> <p>LISTEN to the patient. Remember, their priorities may not be the same as the clinical pathway</p>			
<p><b>Reflective Question</b></p> <p>Margo or was we've talked with her care: once talked with the community learning disability team.</p> <p>What do you think made a difference?</p>	0.50 - 0.55	Reflective qu. 2	Ask the group to consider the question in their small groups.
<p><b>What does good care look like?</b></p> <p>What made the difference when the learning disability team was involved?</p> <ul style="list-style-type: none"> <li>Seeing the need</li> <li>Going there</li> <li>Listening to what mattered most to Margaret</li> <li>Central to Shared Decision Making</li> <li>First task in Shared Decision Making is to give the patient a voice</li> <li>Taking responsibility</li> <li>Multiple professionals involved</li> <li>Exercise</li> </ul>	0.55 - 1.15		Following discussion discuss points
<p><b>What obstructs good care?</b></p> <p>Lots of things:</p> <ul style="list-style-type: none"> <li>Multiple professionals/services involved</li> <li>Risk that no one takes responsibility for key areas of care</li> <li>Understanding information</li> <li>Arranging and attending appointments</li> <li>Offering emotional/practical support</li> </ul>			Recognition of difficulty. Discuss with group some of the things that make good quality care difficult and how we overcome these
<p><b>Tips towards good care</b></p> <p>Assume responsibility</p> <p>Check the basics are covered: understanding, attending appointments, practical support.</p> <p>Who is there to support the patient</p> <p>Offer opportunities to ask questions/voice concerns</p> <p>Think holistically: use the Holistic Needs Assessment tool</p> <p>Recognise patient or carer's goals may not be the same as a clinical clinician</p> <p>Link with the learning disability team</p>			Read through with group and give opportunity to add additional points.
<p><b>Local Contacts</b></p>	1.15 – 1.20	Resources to support group	Discuss with group who they could engage locally to support someone they had identified as needing additional support. (you may wish to prepopulate this slide) Consider: community learning disability team, primary care role, charitable organisations role, support groups...
<p><b>Learning Objectives</b></p> <p>Communication:</p> <ul style="list-style-type: none"> <li>Recognise the needs of people with a learning disability</li> <li>Consider all of good communication tools to meet those needs</li> <li>Consider the barriers to good communication and strategies to overcome them</li> </ul> <p>Delivering high quality care:</p> <ul style="list-style-type: none"> <li>Involving people with a learning disability in their decisions (Shared Decision Making)</li> <li>Taking responsibility</li> <li>Understanding what's available</li> </ul>	1.20 – 1.30	Learning objectives	Revisit to ensure group feel the learning objectives have been reached.
<p><b>Evaluation</b></p>		Evaluation	Ask group to complete evaluation forms