

Margaret's story



Education 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.

Who is this resource for?

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

Access to 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/>

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

Aims of Margaret's story

This film and resource pack aim to provide education and increase awareness of learning disabilities. Allowing people to think about their individual roles within health or social care and how and when they offer support to individuals.

How to use Margaret's story

Margaret's story can be used as a short film watched independently, or as a group education tool.

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 using Margaret's story as part of a group education session we have included a suggested session plan, including questions and opportunity for discussion.

Learning Points

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

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

Finally:

- 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 lesson plan

Time	Suggestion of 45 minutes minimum 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.

Aim	Detail
Introduction	Introduce self to group. If group do not know each other facilitate introductions.
Introduce Margaret's story and aim of session	<p>Possible text: <i>"This session is going to use Margaret's story to help us think about how we support people with a learning disability and in this case a terminal cancer diagnosis.</i> <i>Margaret's story talks about her cancer journey, I will be showing Margaret's story on the screen and stopping at various points to allow us to think about how her experiences relate to our roles.</i> <i>If during Margaret's story or our discussions you need to take some time away from the session please feel free to use the break out room, this is:(explain where the break out room is)</i> <i>Please note this session is about learning from Margaret's story."</i></p>
Play film from start to 03:36 – short version 05:15 - long version	<p>At 03:36 – short version pause film 05:15 – long version pause film. Ask the group to work in small groups of 2 or 3 and discuss: How do you feel about what you have heard so far? Give small groups an opportunity to feed comments to the whole group. NOTE this is about how people are feeling and not about blame.</p> <p>Ask the group to again work in small groups and think about: If they met a person like Margaret tomorrow what could they do to ensure they receive the best possible care and support. Allow feedback into larger group.</p>

	We would like people to identify they could refer to the community learning disability team or the reasonable adjustments they could make.
Play film from pause to end	<p>Once the film has finished ask the group to discuss in their small groups of 2 or 3 how they are now feeling. Allow an opportunity for feedback.</p> <p>Next ask the group to think about their specific area of work and what opportunities there are for them to ensure people like Margaret are given the support they need.</p> <p>After feedback ask the group to identify 1 specific piece of learning they have taken from Margaret's story.</p>
End of session	<p>To end the session ensure people have had the opportunity to have all the discussion they need.</p> <p>Finish with: <i>"Margaret agreed to share her story with us to enable us to stop and think about how we can better support and care for people like Margaret who need a bit extra support or reasonable adjustments. If you wish to share Margaret's story with colleagues, it is available at the Northern Cancer Alliance website at http://www.northerncanceralliance.nhs.uk/resources-cancer-academy/supporting-people-with-palliative-care-needs/"</i></p> <p><i>"Margaret and the North East and Cumbria Learning Disability Network would like to thank you for taking the time to watch and think about Margaret's story."</i></p>
Post session	The web link to Margaret's story can be shared with the group.