West Yorkshire
Health and Care Partnership

Advance Care Planning in West Yorkshire: how we meet the needs of our diverse community

Bebhinn Browne; Senior Programme Manager, West Yorkshire Health and Care Partnership

Charlotte Goulding; Palliative and End of Life Care Programme Manager, West Yorkshire Health and Care Partnership

Agenda

- Welcome and Introductions
- Discussion: What are the current issues in delivering personalised Advance Care Planning/what do you want to get from the session
- Background and Context
  - Policy
  - Need of West Yorkshire Population
  - Aims and Objectives of Training
- Overview of Training and How We Can Change Practice?
- Evaluation and Feedback
- Next Steps – learning for the next cohort
- Examples of advance care planning engagement and training for our patients
- Discussion: What will you take away from today
- Q & A

Discussion

- What experience do you have of providing personalised care?
- What examples of inequalities in Palliative and End of Life Care have you observed in your role?
- How have you started conversations about advance care plans?
- What would you like to learn from this session?

Background: Policy and Context

Ambitions for Palliative and End of Life Care 2021 – 2026 & Universal Principles for Advance Care Planning, 2022

1. The person is central to developing and agreeing their advance care plan including deciding who else should be involved in the process.
2. The person has personalised conversations about their future care focused on what matters to them and their needs.
3. The person agrees the outcomes of their advance care planning conversation through a shared decision making process in partnership with relevant professionals.
4. The person has a shareable advance care plan which records what matters to them, and their preferences and decisions about future care and treatment.
5. The person has the opportunity, and is encouraged, to review and revise their advance care plan.
6. Anyone involved in advance care planning is able to speak up if they feel that these universal principles are not being followed

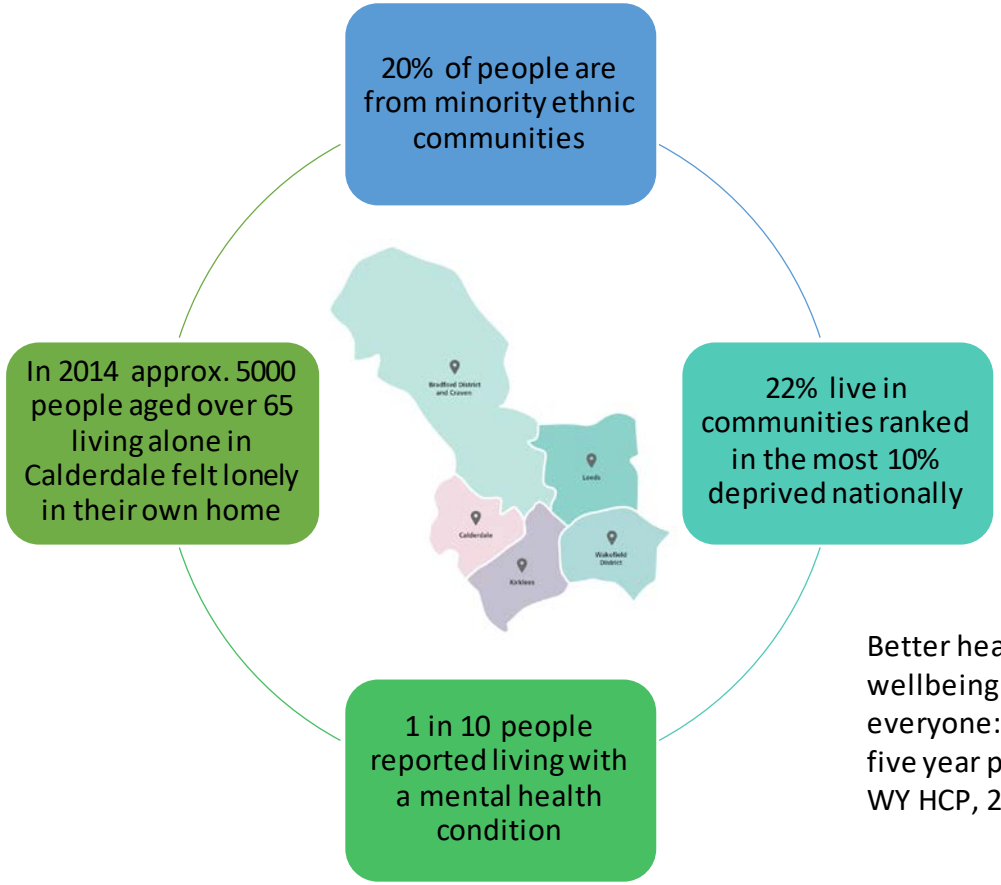
Background: West Yorkshire Population Needs

A Marie Curie review focusing on inequities in palliative care found that certain groups of people receive less palliative care than others with a comparable need. These are people who are;

- Over the age of 85
- From minority ethnic backgrounds
- Identify as LGBT
- Are from more deprived areas
- Are socially isolated or live alone
- Are homeless
- Have mental health needs
- Are living in prisons

Marie Curie (2021) Inequalities in palliative care - Deprivation

In West Yorkshire;



Better health and wellbeing for everyone: Our five year plan, WY HCP, 2019

Background: West Yorkshire Population Needs

West Yorkshire ICB Connected on Inclusion report, 2022, identifies that people from ethnic minorities need to be involved in discussions about access to end of life care

Recommendations from Elderly and End of Life Care for Muslims in the UK - Muslim Council of Britain (MCB), 2019 research recommended PEoLC services better understanding:

- how faith and culturally based preferences can be supported
- why there is poor uptake of advanced care planning

Key findings from the Bradford Inequalities Research Unit included;

- Increase death awareness as a community issue through public information
- Provide additional training and support of the health team in instigating ACP
- Develop understanding of how end-of-life discussions can be normalised within the community.
- Use strategies to implement and encourage end-of-life care discussions amongst family members

How Do People from the South Asian Community view, use and understand Advance Care Plans? How ready are they to use these advance care plans alongside other palliative care support? 2021 BIRU EoL Report_11.10.2021.pdf

Background: Personalised Care Workforce Training

The aims of our wider personalised care training offer are;

Background: Advance Care Planning and Bereavement Training

Aim;

- Upskill our health and care workforce to deliver Personalised Care in the context of end-of-life care, advance care planning and bereavement

Objective;

- Enable and encourage better conversations between health and care professionals, people and carers about end of life, advance care planning and bereavement in a way that is accessible, carer focused and supportive of what matters to people

Background: Advance Care Planning and Bereavement Training

The training was adapted from a previous training programme to the needs of the voluntary sector, health and social care roles, in particular additional roles in primary care including care coordinators, health coaches and social prescribing link workers, roles which are critical in supporting these outcomes.

The Education team at St Gemma's aim was to develop and deliver a high-quality, virtual and interactive training, to develop the wider workforce to gain understanding of personalised care within end of life care and comprises of 4 modules

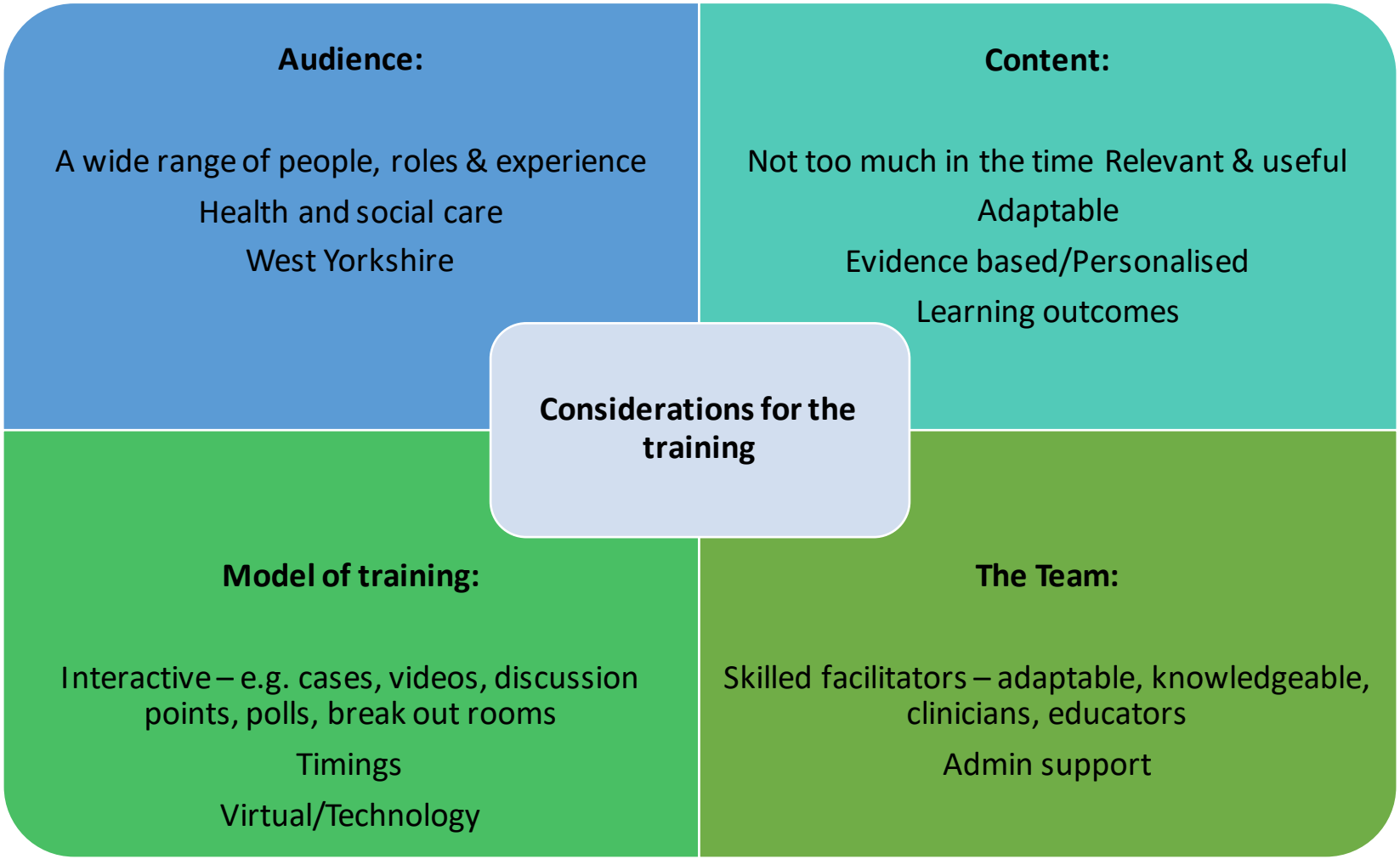
Background: Advance Care Planning and Bereavement Training

The training sought to develop a highly skilled cohort of professionals able to deliver better conversations about bereavement and advance care planning by being inclusive and meeting the diverse needs of our communities. Following a procurement exercise St Gemma's was appointed to deliver training to 200 health and social care staff

The course includes modules on:

Advance Care Planning	• Including use of clinical systems to record and share advance care plans
Difficult Conversations	• How to use communication skills in situations we find difficult & challenging
Last Days of Life	• Supporting unpaid carers of those in the last weeks and days of life
Bereavement & Loss	• Different reactions to loss and including self-care

Background: Considerations for Training



Example Content: Challenging questions/ allowing the person to talk

What do you do if someone asks you a question that you find difficult to know how to answer?

Am I dying now?

First part; https://youtu.be/VbLSLSup3HA

- **Notice what was good / anything not so good/ how would you answer?**

Example Content: Challenging questions/ allowing the person to talk

How Would you Answer?

1. Don’t worry about that now, let’s make you comfortable
2. I don’t know shall I get one of the doctors to see you
3. Is that what you feel is happening now?

Second part; https://youtu.be/vO13fZNII5c

- **How she answers/ what skills she is using and the impact**

How We Included Personalisation and Inequalities

Whole essence and philosophy of Palliative Care is a personalised approach. What does this look like? How do I do that? Some examples:

ACP

- WYH video covers diversity and has someone living with dementia talking on it.
- Discuss dementia when looking at disease trajectories & the importance of planning early

Communication skills

- Each interaction is personal and this can be influenced by many things, we discuss what…
- How to use an interpreter

Bereavement and Loss

- What people with learning disabilities need and other vulnerable groups
- Influences and Individual responses to grief

Last Days of life

- Discuss pain assessment in cognitive impairment/non verbal
- How to give a holistic approach to the person

Training Data

292 people have attended at least one training module so far, each module has an attrition rate of approximately 50%;

Professions	
Role	Number of People
Other health care professional	115
Nursing Staff	108
Social Work Staff	27
Medical Staff	17
Occupational Health Staff	11
Paramedics	7
Physiotherapists	6
Podiatrists	1

Module Bookings		
Module	Number who Attended	Number who Didn't Attend
Supporting Personalised Care and ACP	42	36
Difficult Conversations	26	25
Care of Patients in Last Weeks	41	38
Bereavement and Loss	44	37

Evaluation and Feedback

NHS West Yorkshire Integrated Care Board

1. Live poll – 3 closed questions at the end of the session
2. Immediate survey post session – open questions, gives more content/ number completed/ examples/ any figures
3. Post course survey- impact/ application into practice 3 months after training

- ✓ **100% of attendees stated the session met their expectations**
- ✓ **100% of attendees stated they would recommend this session to a friend or colleague**
- ✓ **100% of attendees stated they would be able to use this information in their day to day practice**

Survey Comments

"I gained a lot of new knowledge to pass on to other people. Very informative, I gained lots of new information and now feel more confident when talking to and helping others."

"I gained a lot of new knowledge to pass on to other people. Very informative, I gained lots of new information and now feel more confident when talking to and helping others."

"Very engaging, getting us involved and to hear other professionals ideas and answers"

"Pitched perfectly for all levels in the group. Really thought provoking"

"Much more information that I had expected. I feel I am more than capable now with the right tools and knowledge to start this conversation. The course was delivered in a very friendly manner, with good information and a wealth of knowledge from the presenters who have much to offer in their experiences. I can take a lot away from this."

"Very well presented and informative. It certainly made me realise the importance of ACP and I would like to support others. Good that there is ongoing support if we need it. The course leaders were very good and put across the points in an informative but empathetic manner."

Changes/Modifications to Training

Informed by feedback given in session and in evaluation surveys from people attended and also facilitators who delivered the sessions

- Case studies simplified
- Opened up to more people
- Reduced some content = more discussion time
- Resources added in. Some new ones found
- Increased content about Learning Disabilities in B&L

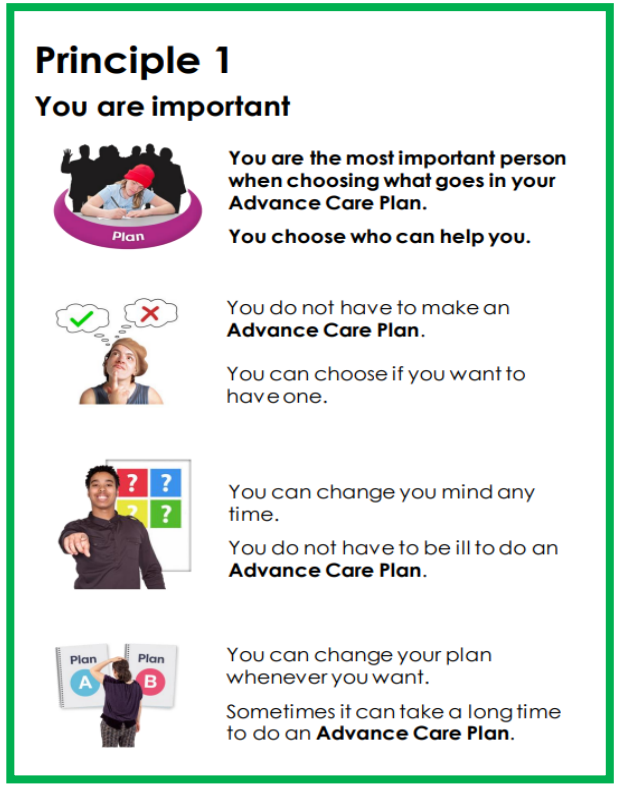
Future Plans

NHS West Yorkshire Integrated Care Board

- Review with the team
- Deliver the second phase – 16 sessions (4 of each area)
- Increasing session intake to 30 people per session to accommodate drop out rate
- Produce an evaluation report about the full programme (28 sessions)

Making a plan for your health and care if you become very ill – easy read

NHS West Yorkshire Integrated Care Board



https://www.england.nhs.uk/wp-content/uploads/2022/03/universal-principles-for-advance-care-planning-easy-read.pdf

Advance Care Planning with our communities

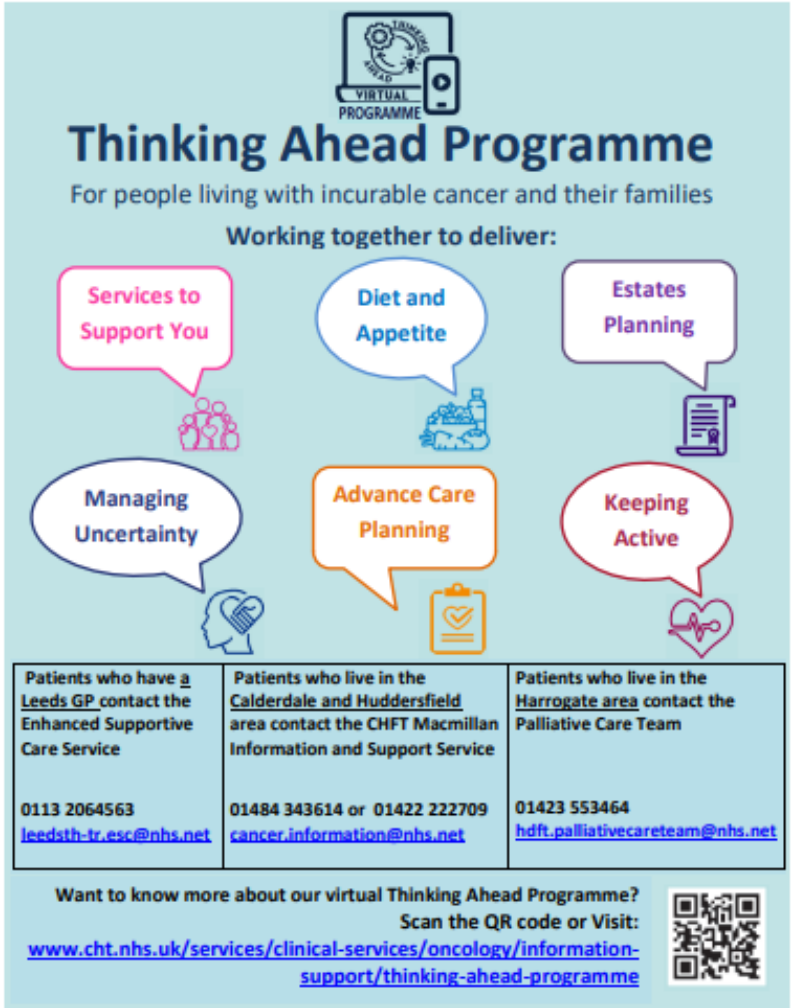
NHS West Yorkshire Integrated Care Board

Advance Care Planning - Urdu

Advance Care Planning – Punjabi

Advance care planning training for patients

NHS West Yorkshire Integrated Care Board



- For any patients with an incurable cancer diagnosis, who may or may not be receiving active cancer treatment, from the Harrogate, Leeds and Calderdale and Huddersfield areas.
- Family members/carers are also welcome and encouraged to attend, and some family members attend the course without the patient wanting to join.

Next Steps

NHS West Yorkshire Integrated Care Board

- ✓ Continuing the training for 2023/24:
- Involving people with lived experience to evaluate the course content and to support the training as facilitators
- Considering course content relating to inequalities
- Asking for case studies to demonstrate how learning is used in practice
- ✓ Embedding advance care planning and personalisation across our West Yorkshire 2022 – 2026 programme plan and vision of PEoLC

Discussion

NHS West Yorkshire
Integrated Care Board

- What have you learnt from today's workshop?

- How will you use learning in your practice?

NHS West Yorkshire
Integrated Care Board

Thank you for listening

Do you have any questions?

Reflecting as you travel home

NHS
North East & Yorkshire
Palliative and End of Life Care Strategic Clinical Network

Reflecting on all the sessions you have heard today take a moment to consider.

- What have you learnt that you did not know before or what inspired you the most ?
- What will you take back to your workplace and consider implementing or improving in practice ?
- What from what you heard today might be key priorities for your organisation?
- What could be the challenges to meeting these priorities ?

Future Sessions – Lunch and Learn

NHS
North East & Yorkshire
Palliative and End of Life Care Strategic Clinical Network

- **19 October 2022**

Sue Bottomley National Programme Director palliative and end of life care
Topic- ICB statutory guidance PEoL and commissioning and contracting

- **9 November 2022**

HEE colleagues
Topic- Nurse apprenticeships and nursing associate opportunities

- **E mail Stephanie Beal** stephaniebeal@nhs.net for the link

NHS
North East & Yorkshire
Palliative and End of Life Care Strategic Clinical Network

Evaluation

Please help us by competing the evaluation for the conference by using the QR code attached. (Copies are also on the tables).

We welcome your feedback!

Scan me!

Staying up to date

NHS
North East & Yorkshire
Palliative and End of Life Care Strategic Clinical Network

NHS Futures National End of life Care Practitioners Network
E mail: Sherree.Fagge@nhs.net to join

To be added to the SCN distribution list for future webinars,
E mail: stephaniebeal@nhs.net

To suggest topics for future L*unch and Learn* webinars,
E mail: marie.hancock2@nhs.net

Please use our website.
https://www.yhscn.nhs.uk/palliative--end-of-life-care-clinical-network