

Dying Matters – Let's Talk About It Engagement Summary Report

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March 2018

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Introduction

Wigan Borough Clinical Commissioning Group (CCG) is responsible for assessing Wigan Borough peoples needs and monitoring high quality healthcare services.

In 2017, Wigan Borough CCG started to develop the End of Life strategy to include how we help people prepare for their end of life. End of life care is support for people who are in the last months or years of their life. The strategy will cater for people who require;

- Services for people who die suddenly or unexpectedly.
- Services for adults and children nearing or planning for end of life.
- Support for families and loved ones of people who are dying.
- Services for people who have an illness which is life limiting and they are receiving help to improve their quality of life (this is called palliative care).
- How we help people to talk about their wishes and choices earlier and plan the end of life. This will be a 5 year strategy that will be reviewed on an annual basis.

In February and March 2018 we engaged with patients and residents to understand what is important to people when it comes to End of Life matters. This report summarises what people told us.

The team writing the strategy will feedback how the information gathered is used and this will be fed back to people who gave us their views.

How have we involved people?

We held 3 workshops last year with staff from different services to assess how we are performing in Wigan Borough against the National Ambitions of Palliative Care and End of Life.

We met with 3 Patient Representatives who shared their experiences and helped us design the engagement questions.

We collected 3 patient / family stories to be included in the strategy.

We held a workshop session with 11 people at our Wigan Borough CCG Patients Forum.

We launched a survey aimed at patients and members of the public. We got 55 responses to the public survey.

We commissioned Healthwatch Wigan and Leigh to undertake 7 discussion sessions out in the community. They spoke to a total of 45 people across these sessions. Healthwatch have produced a report to summarise these discussions.

We launched a survey aimed at staff working in local services. We got 30 responses to the staff survey.

Terry and Elaine's story...

I met Elaine at Leeds University where we were both mature students and within 18 months we got married.

Elaine had her first stroke in May 2012. She seemed to be making a good recovery and was keen to get back to work as a teacher. Over time she started to deteriorate mentally. We saw a specialist and he showed Elaine the X-rays of her brain. We saw there was a big white blotch and the doctor told us he was surprised Elaine was able to walk and talk.

Unfortunately after that Elaine had several more strokes and was in and out of hospital. Towards the end of a lot of upsetting times, I found myself sat next to Elaine in a bed, she was in a side ward and was comatose. I was reading to Elaine when the team came to me and asked if I thought Elaine was hearing or responding to me. They informed me they would pass Elaine over to the Palliative care team who would take it from there. I was in a state of shock. In the space of 9 months Elaine had gone from being a vibrant working woman to being comatose in hospital. The term palliative care didn't mean anything to me and I wasn't in a place to ask them.

I only realised Elaine was dying at a later time when the doctor was talking to me and he got the X-ray and I saw that half of Elaine's brain was damaged. I hadn't understood initially that Elaine was dying and that I needed to make arrangements – this only became clear when I saw the scan.

The last 3 weeks I was desperately grateful that Elaine was in a side ward because the thought of her being on display on her last days would have been heart breaking to me. I was approached by the staff in the ward who very kindly, but insistently, said that Elaine could not stay here and we needed to find somewhere else. They told me not to worry and that the NHS would pay for it and they asked me to go in the next day to speak to the Social Worker. The following day the Social Worker gave me 3 – 4 sheets of paper with addresses for care homes, there was no other information.

Terry and Elaine's story...

Over the next days I walked the streets of Wigan looking for somewhere for Elaine to die. I asked one of Elaine's carers who suggested a place to me. I went to the first home and the place looked okay but staff were busy. I went to the second home and knew straight away it wasn't for Elaine. Looking again at the list I saw that there was somewhere closer to our home. By this time I was beyond despair. When I got to the third home they told me this type of establishment wasn't what we needed for Elaine. The lady told me that her mother in law had gone into a local home that she would strongly recommend. When I went there, the staff were great and I liked the atmosphere so I arranged for Elaine to go in there. Whilst I was happy with the home I chose eventually, the experience of finding it was very traumatic.

I knew when Elaine was due to be transferred to the home from hospital. The day before the transfer, I took perfume, a vase, and her favourite music up to the home ready for her arrival because the next day was Valentine's Day. The home telephoned when Elaine arrived. I picked up some flowers on the way and when I arrived I sprayed the perfume and sorted the flowers out. I then left the room for 5 minutes to go to the office to speak to a member of staff. When I went back into Elaine's room she had passed away.

Over the period of the last few weeks I had been called into the hospital on several occasions as staff thought Elaine was close to death, but Elaine was stubborn and rallied. I take some comfort in the fact that the last thing to happen in Elaine's life was me taking flowers and spraying her favourite perfume.

I can't express enough how much praise I have for all the teams that looked after Elaine, they were fantastic. I wouldn't want the negative aspects that I have described to take away from my gratitude to the NHS. However, if there are things I hope will change;

- That staff will be aware loved ones might not take in the information being given about the person's condition or might not understand terms like Palliative or Holistic care.
- That no other family will go through being handed sheets of paper with addresses for care homes without support or advice.

Patients Forum

This session was attended by 11 people plus members of the project team working on the strategy. The purpose was to gather the views of members and to test the public survey questions. The discussion resulted in some changes being made to the public survey before it was published.

Would you feel comfortable discussing end of life with those closest to you? (emerging themes):

- Mixed response between yes and no.
- Need to change culture in society to being more open to talk about it and start with younger generations.

If you needed information on End of Life, who would you speak to or what would you do? (emerging themes):

- Range of answers, including online and from health professionals.
- There needs to be information readily available about this in a range of formats.

Things most important at the End of Life:

Pain free

Wishes and choices honoured

Privacy

Dignity

Peace

Faith

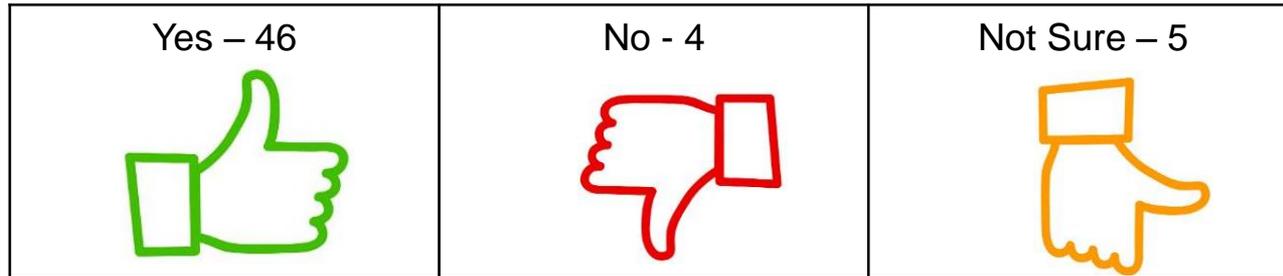
Support for family

Have people heard of Palliative Care and Advance Care Planning, and do people understand what they are:

- Generally no.
- Need more work around this and to make sure patients/families are told what this means.

Patient and Resident Survey Results (55 responses)

Q1. Do you feel able to talk about End of Life with those closest to you? (55 responses)



Q2. Why have you selected that answer? – (53 responses)

The themes emerging from those who DO feel comfortable;

1. General discussion in the family.
2. Having a professional background in healthcare.
3. Spiritual / Religious beliefs.
4. Previous End of Life experiences.

The themes emerging from those who DON'T feel comfortable or AREN'T SURE;

1. Uncomfortable.
2. Don't know how to approach it.

Q3. If you needed information about preparing for end of life for yourself or a loved one, who would you speak to or what would you do? (54 responses)

The most popular answers;

1. GP.
2. Books & Internet.
3. Family.
4. Don't know.
5. Macmillan.
6. Solicitor.
7. Priest.
8. Hospice.

Other points noted;

- Friends.
- Undertakers.
- Work colleagues.
- Professionals.
- My children.
- Hospital.
- Next of kin.
- Healthwatch.
- Schools.
- Library / Community Centre / Council Buildings.

Q4. What 3 things would be most important to you and your loved ones at the end of life? (54 responses)

The most popular answers;

1. Pain free.
2. Treated with respect and dignity.
3. Making sure family with bereavement.
4. Personal wishes.
5. Being at home.
6. Funeral arrangements, including having enough money.

Other points;

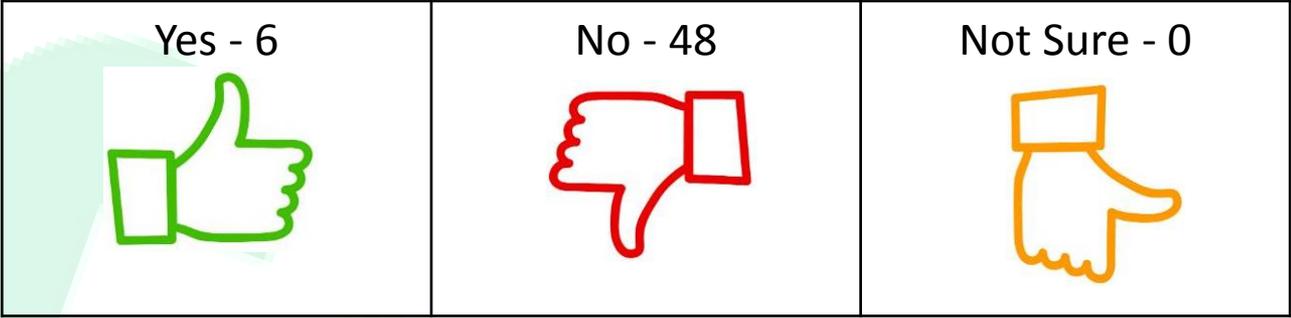
- Faith.
- Financial arrangements made to support family.
- Dying in sleep.
- Peacefulness.
- Being in familiar surroundings.
- Choice of death, where and when.
- Pets are looked after.
- Do Not Resuscitate.
- Organ donation.
- Medical staff respecting wishes.
- Good symptom control.
- Access to Macmillan services.
- Professional guidance.
- Advice for family.
- Communication.
- Assisted death.
- Fulfilling achievements.

Q5. What concerns do you have about preparing for end of life for yourself or a loved one? (51 responses)

The most popular answers:

- 1. Being overruled.
- 2. Family grief.
- 3. Nothing.
- 4. Pain.
- 5. Preparation / Plans.
- 6. Financial.
- 7. Location.
- 8. Burden to family.
- 9. Facility being available.

Q6. Has a Healthcare professional talked to you about Advance Care Planning? (54 responses)

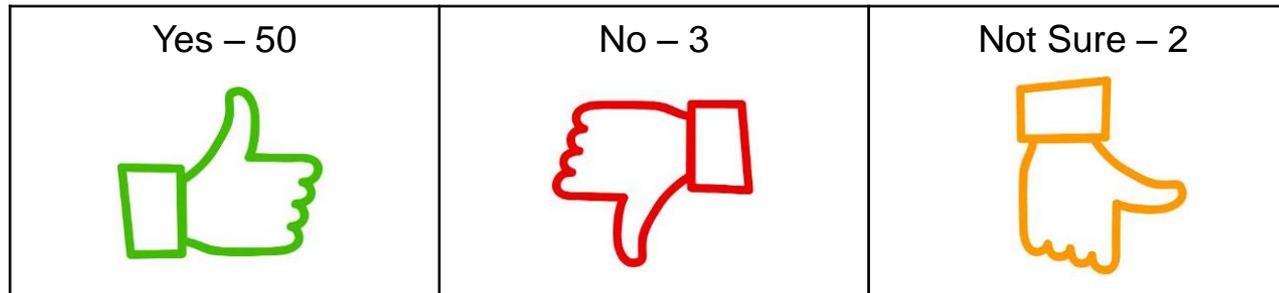


Q7. If so, what do you know about it? (11 comments received)

The most popular answers:

- 1. Limited knowledge.
- 2. Support available.
- 3. How I would like to be cared for and made comfortable.
- 4. Wishes and concerns.
- 5. Pain management.

Q8. Have you heard of Palliative Care? (55 responses)



Q9. If yes, what does it mean to you? (46 comments received)

1. Symptom relief / keeping someone comfortable.
2. Pain management.
3. For those with a terminal illness for which there is no cure.
4. Necessary / approaching the end.
5. Choice and wishes (planning).
6. Support.
7. Dignity.
8. Best quality of life possible.
9. Keeping people alive with no quality of life / dignity.
10. Withdrawal of life support.
11. Giving Up.
12. Integrity.
13. Compassion.

Other comments – need to communicate this clearly and make sure family/loved ones understand what it means.

**Q10. Sharing experiences –things might have been handled well or where things could be improved?
(40 responses)**

Things that went well	Things that didn't go well	Other Points
<p>Good communication. Having time with relatives. Talking about it. Good Primary Care. Support for death at home. Compassionate care. Being surrounded by family. Dying in preferred location. Support from District Nurses. Support from Palliative care nurses. Having an Advance Care Plan. Support from Derian House.</p>	<p>Viewing body in A&E with cannulas and tag still in place after a sudden death. Communication, including support and lack of explanations. No identified support. Funding for funeral of suicide or sudden death. Nurse came over as being abrupt. Psychological impairment made understanding diagnosis difficult. Hospital setting. Communication support related to choice of care home was poor. Lack of identification of early onset Dementia caused difficulties with personal choices late in pathway. Lack of clear communication between mortuary and hospital staff. Dying on ward with curtains pulled. Staff lacking sensitivity. Issues with pain management. Better explanation of what nurses are documenting.</p>	<p>Hospice in Care Home should be rolled out nationally. Need to repeat important information to loved ones when breaking bad news or sharing important information. Patient was not at a local Hospital which made travel difficult. When visiting End of Life patient relative required clinical support which was delayed. Medical practitioners need to follow guidelines. Government funding for Hospice Care. Unexpected deaths – families sometimes experience lack of support. Need staff who can reassure relatives in last days of life. Need for respite and night sits. Information related to organ donation. Thoughts around Assisted Dying.</p>

Q11. Is there anything else you would like to tell us? (29 responses)

- Know more about palliative care in Wigan.
- Information to help families understand the process to access care homes, costs and availability or financial support and how to access social care.
- Make patients and family more aware of the support available in the local community (coming to terms with diagnosis, emotional and physical difficulties).
- Worry about my own End of Life and would like to be able to book a Hospice bed.
- Earlier discussions around Do Not Resuscitate would be better to avoid discussions when the patient is sick.
- Educate children and young people to plan for End of Life.
- Telling people things will get better does not help them through.
- Enjoyed end of life training and shared it with family.
- More information needed about how to register wishes.
- Society needs to get to the point of feeling comfortable talking about dying.
- Referendum on assisted dying needed.
- There should be one pack of documents – ‘All you need to know and do when death happens’.
- The Registrar was helpful and contacted other agencies on my behalf, but I found it upsetting when I started to receive letters from these agencies and I would have found it helpful to have been told to expect to receive letters.

Who responded to the survey? – demographic information

Postcode
M28 - 1
M29 - 4
WA3 - 5
WN1 - 2
WN2 - 7
WN3 - 6
WN4 - 5
WN5 - 6
WN6 - 8
WN7 - 3

Ethnicity
White British - 48
Welsh - 1

Sexual Orientation
Bisexual - 1
Heterosexual - 32

Gender	
Female 32	Male 17

Gender Identity the same assigned at birth?
100% Yes

Age
18-29 - 2
30-39 - 2
40-49 - 3
50-59 - 15
60-69 - 13
70-79 - 13
80-89 - 1

Religion
Atheist - 2
Church of England - 9
Christian - 8
Catholic - 6
Methodist - 2
None - 9

Relationship Status
Engaged - 1
Married - 32
Single - 5
Widow - 7

What type of disability?
Hearing - 5
Visual - 1
Long term condition - 6
Communication - 1
Mobility or physical - 2

Employment Status?
Employed - 19
Retired - 28
Unemployed - 1

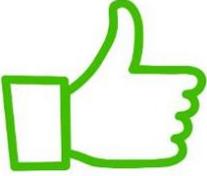
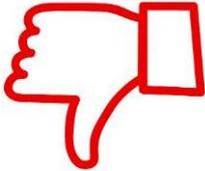
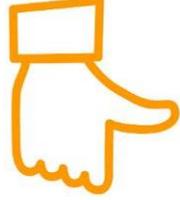
Veteran
No - 41
Yes - 4

Carer
No - 36
Yes - 12

Disability	
Yes 11	No 36

Staff Survey Results (30 responses)

Q1. If a patient or members of the family approached you would you feel comfortable talking about end of life issues with them? (30 responses)

Yes - 26 	No - 2 	Not Sure - 2 
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Q2. What skills do you feel you have to support a person who requires advice and support? (30 responses)

Ranked by popularity

1. Common sense (26).
2. Life experiences (26).
3. Previous experience of death in the family (25).
4. In house training (17).
5. Advance patient communication skills course (15).
6. Spiritual or community leader (3).
7. Counselling qualification (2).

**Q3. If at any point you felt you did not know the answer to the questions what would you do?
(30 responses)**

Ranked by popularity:

1. Signpost the person to an individual or service that will be able to help (29).
2. Tell the person you don't know the answer (12).
3. Tell the person not to worry (1).

Nobody selected the option 'Reassure the person they probably don't need to know that'.

**Q4. Please indicate in order of priority which of the 6 End of Life Ambitions require improvement?
(30 responses)**

Ranked by popularity (weighted):

1. Maximise comfort and wellbeing.
2. Each person is seen as an individual.
3. Each person gets fair access to care.
4. Care is coordinated.
5. All staff are prepared to care.
6. Each community is prepared to help.

Q5. What do you feel could be improved for your top 3 priorities? (21 responses)

Themes (Most popular):

1. End of life training / education (needed at all levels, including need for palliative care education team and it needing to be more of a priority).
2. Communication (e.g. for better coordinated care and professionals speaking to each other).
3. Access (including Single Point of Access).
4. Patient / Family being made comfortable and pain free.
5. Timely intervention and access to treatment (e.g. beds).

Other comments:

- More staff to assist at home.
- Services pro active in providing care.
- GPs better understanding of anticipatory drugs.
- Funding for services consistent for all patients (end post code lottery).
- Ensure patient centered and compassion.
- Everyone is involved in palliative care.
- Patient Choice.
- Appropriate referrals to teams.
- If hospitalised, at handover, staff should meet with the patient/family rather than receive hand over privately.
- One case worker clinically trained to manage End of Life.
- Timely administration of drugs.
- More convenient locations for people to access services.
- Individual care plans & more family involvement.
- Services being aware of other appointments / care.
- Advance Care Planning is not just palliative care responsibility.
- Better staffing levels on wards.

Q6. What does Advance Care Planning mean to you? (30 comments received)

The top 2 themes were around;

1. A person's preferences – documenting/understanding the preferred place, treatment, medication, wishes, funeral arrangements, financial needs, spiritual needs.
2. Planning – some of the specific comments around planning related to knowing what to put in place if a patient moved to palliative care, to enable quick access to services and medication, having everyone's contact details, avoiding future crisis and making sure everyone is clear on all the above.

Some other comments were around;

- Patient Choice.
- Enabling informed decisions.
- Communication, with families and between professionals.
- Patient/family being in control of how, where and what happens.
- Preparing the family.
- Preparing for any and every eventuality.
- Enabling staff to confidently support someone.

Q7. Who do you feel would arrange Advance Care Planning and why? (30 responses)

The top 2 themes were around;

1. Any / All healthcare professionals should do this (with appropriate skill, confidence, training).
2. The patient/family at the centre – with help, support and in collaboration with services.

There were some other comments about who people thought should lead on this, including;

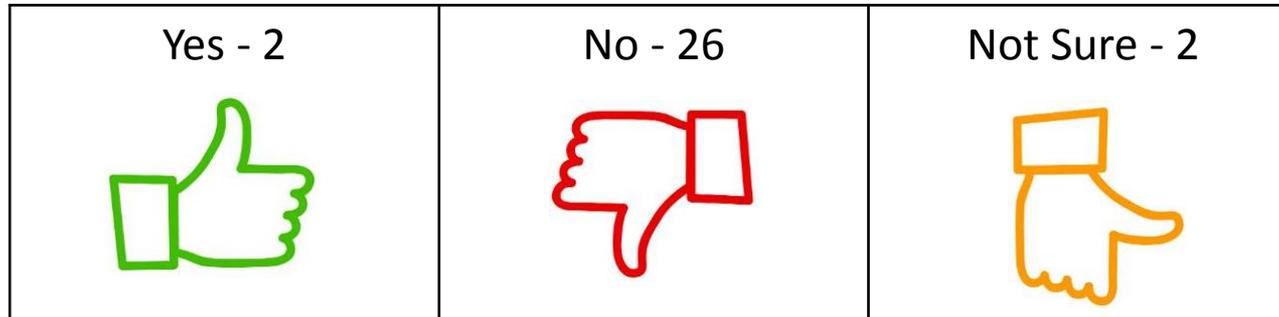
- Community Services leading the process.
- Palliative Care Team leading the process.
- GP leading the process.
- Key worker.

Q8. If you had responsibility for arrangements following a death who would you look to help you understand what is required? (30 responses)

Ranked by popularity;

1. Funeral Directors (28).
2. Hospice/ Care Home or community staff (20).
3. Member of family (19).
4. Bereavement officer (11).
5. Hospital nursing staff (10).
6. Registrars of deaths (10).
7. Friend who has experienced death (8).
8. Spiritual leader (8).
9. GP surgery (8).
10. Hospital medical staff (7).
11. Coroner's office (5).

Q9. Do you think the process is the same for expected deaths and sudden deaths? (30 responses received)



Q10. Is there an issue related to End of Life or an experience you would like to share so we can help others? (12 responses received)

- More support for families / loved ones, before, during and after losing a loved one.
- Prescriptions being wrongly prescribed with regards to end of life medication and new guidelines (i.e. Diamorphine rather than Morphine).
- The importance of supporting the patient/family wishes with regards to treatment/care.
- Availability of end of life drugs at Pharmacy and families sometimes having to travel around.
- Regular, ongoing communication with the patient and family as early as possible.
- Communication and support offered by staff, including the police.
- Better signposting / information available for families and what they need to do.
- All professionals should have the same end of life training.

There was one practical experience shared that they wanted to make staff aware of; Once a deceased person has been verified as 'Life Extinct; by the appropriate trained healthcare professional then the family (next of kin) have the right to legally remove them to their preferred place. They need to contact the police to advise they are transporting the body and the route and they must also have documented proof that verification of death has been undertaken prior to removal of the body.

Q11. Where do you work? (29 responses)

- NHS – 1
- North West Boroughs – 1
- Hospice – 11
- Wigan Borough CCG – 3
- General Practice – 1
- Community – 5
- Out of Hours – 1
- Complex cancer and palliative care team – 1
- Platt Bridge Health Centre – 1
- Wigan Clinic - 1
- Wigan Council (Public Health) – 1
- Wrightington, Wigan and Leigh NHS Foundation Trust - 2

Next Steps

This report and the report from Healthwatch Wigan and Leigh will be made available to the project team working on the End of Life Strategy. The things that people have told us will be considered and will inform the strategy.

The project team will be asked to explain how the information is used and we will publish this so people are made aware of the contribution they have made to the strategy.

Overall there are some clear themes emerging that we think the project team should consider;

- Communication with patients and families – including explanations of terms and services available.
- Process of support given to patients / families on finding care / nursing homes.
- Encouraging people to be more comfortable discussing End of Life (including knowing what Advance Care Planning and Palliative Care is).
- Information on End of Life readily available in one place in a range of formats.
- Describe how the strategy will concentrate on key priorities identified by the people, carers and staff of Wigan Borough related to end of life experience and bereavement issue important to them.
- End of life training and education for staff (consistent across services and different levels of staff).
- Improve communication between services.
- Look at access issues around different services.
- Look at issues staff reported around end of life medication, both prescriptions and availability of pharmacies for families.
- Engagement and involvement of faith groups.