



**Walsall Together: End of Life & Palliative Care Pathway
Family Member / Loved Ones Engagement Report**

March 2022

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Acronyms

LD CHC	Learning Disability - Continuing Healthcare
DN	District Nurse
OT	Occupational Therapist
DNACPR	do not attempt cardiopulmonary resuscitation
CCG	Clinical Commissioning Group
MH Advocate	Mental Health Advocate
EOL	End of Life
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment.

1. INTRODUCTION

1.1 Walsall Together is an integrated care partnership between the organisations that plan and deliver health, mental health, and social care services locally. They include:

- Walsall Healthcare NHS Trust
- Black Country & West Birmingham Clinical Commissioning Group (CCG)
- Local GPs & Primary Care Networks
- Black Country Healthcare NHS Foundation Trust
- Walsall Council
- Walsall Housing Group (whg)
- One Walsall

1.2 One of the key aims is to help the population of Walsall stay well for longer but also to:

- Improve the health and wellbeing outcomes of the population.
- Increase the quality of care provided.
- Provide long term financial sustainability for the system.

1.3 Healthwatch Walsall is an independent champion for people who use health and social care services, and the role includes finding out what matters to people and help make sure their views shape the support they need. Healthwatch Walsall has been commissioned by Walsall Together to capture the patient and service user voice around care pathways and living and managing with long-term health condition(s). The focus has been on the 6 priority Key Lines of Enquiry around Diabetes, Respiratory, Cardiology, Mental Health, End of Life and Palliative Care and the best start in life, early child.

This report contains the outcome of engagement work undertaken in relation to loved ones and family members experiences of end of life / palliative care in Walsall and details some recommendations for end-of-life care pathway improvements for commissioners and providers of end-of-life services to consider and respond to.

2. WALSALL END OF LIFE STRATEGY

2.1 Death and dying are inevitable. The quality and accessibility of this care will affect all of us and it must be made consistently better for all of us.

“How we care for the dying is an indicator of how we care for all sick and vulnerable people”

(National End of Life Care Strategy 2008)

2.2 Walsall has a developed End of Life Strategy 2018 – 2023. Underpinning principles for the strategic goals identified within the Strategy are:

- It applies to wherever the patient and carer are receiving care.
- Unless otherwise stated all references are to people who are in the last year of life.
- The actions apply to all people regardless of diagnosis and cultural background.
- The strategy applies to all partnership organisations in Walsall and is inclusive of the broad Voluntary and Community Sector that exist as means of support.
- Responsibilities in all actions apply to both patients and carers.

2.3 Progress has been made in the last five years with Palliative and End of Life Care within the Borough. The principle for this strategy is that it continues to focus on previous priorities but now identifies key strategic objectives which will deliver greater continuity, response and improved communication for patients, carers, and professionals.

2.4 The emphasis of the Walsall End of Life Strategy is on local decision-making and delivery, core to its centre are the needs of people of all ages who are living with dying, death and bereavement, their families, carers, and communities which must be addressed, considering their priorities, preferences and wishes.

2.5 Taking this into account as part of the end-of-life strategy engagement with family members and loved ones is an essential part of the end-of-life strategy.

3. END OF LIFE STRATEGY KEY PRIORITIES

3.1 There are 5 key priorities identified within the end-of-life strategy. These priorities are to be used as part of the engagement with those who are important to the patient.

I. Recognise

The possibility that a person may die within the next few months, days, hours are recognised and communicated clearly, decisions made, and actions taken in accordance with the persons needs and wishes, these are reviewed regularly, and decisions revised accordingly.

II. Communicate

Clear and sensitive communication needs to take place between the person who is terminally ill and those identified as important to them. This includes identifying the extent of the persons need for information and allowing them to decline discussion regarding the possibility that they may be dying.

III. Involve

Terminally ill patients and those identifying as important to them are involved in decisions about treatment and care to the extent that the dying person wishes.

IV. Support

The needs of family and others identified as important to the person that is terminally ill are actively explored, respected, and met as far as possible.

V. Plan & Do

An individual's plan of care is agreed, co-ordinated and delivered with compassion (including food and drink, symptom control, psychological, social, and spiritual support).

Through the development of the survey for engagement purposes we encompassed some of the questions based around the 5 key priorities as identified in the end-of-life strategy.

4. VOICES QUESTIONNAIRE

4.1 There is a national and abbreviated local questionnaire capturing the views from those who are important to the patient in relation to their end-of-life care pathway. This is a more in-depth tool used to capture experiences. It is recognised that the Voices questionnaire is used and recognised nationally and locally as an essential element within the end-of-life strategy.

4.2 This engagement was not intended to supersede engagement around the voices questionnaire but to add value to engagement.

4.3 An agreed approach to engage with patients / those important to them through:

- One to one telephone conversations
- Community outreach
- Surveys

4.4 The survey that was used as part of the engagement was shared with the Palliative Care Team and End of Life Working Group for comments before it was made live.

Through these mechanisms our aim was to capture qualitative data from participants, family members experiences, values, and views of their loved one's care pathway.

5. TARGET AUDIENCES

5.1 As part of the engagement we defined our target audiences as:

- Carers
- Family Members
- Those who are important to the patient.

5.2 We endeavoured to be clear with participants about the rationale for capturing experiences, but most importantly that the aim of the intelligence is to improve patient and family / loved one's experiences in the future of end of life and palliative care.

5.3 The questionnaire was devised with open text boxes for the participant to free type experiences.

5.4 We recognise that discussing end of life is an emotive subject. Whilst capturing the views from participants we were able to signpost to other care professionals.

6. METHODOLOGY

6.1 This report is the culmination of engagement work undertaken and co-ordinated by Paul Higgitt, Senior Engagement Lead, Walsall Healthwatch, and Phil Griffin, Walsall Together Service User Group Chair. It is based upon several family members views and experiences of end of life and palliative care.

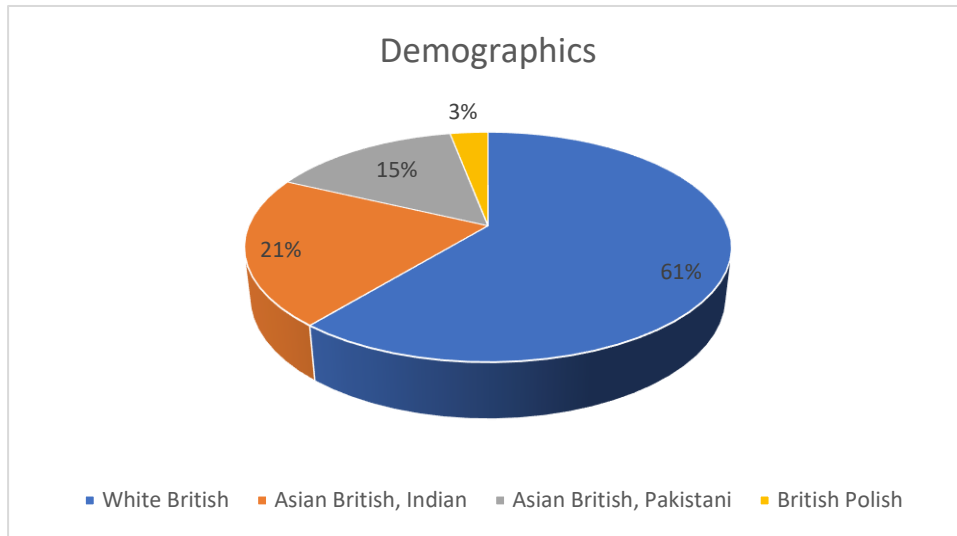
6.2 We engaged with 41 family members / loved ones and captured a large amount of qualitative data on care pathways, and this has highlighted similar patterns in family members and loved one's experiences in the quality of care.

6.3 Through our work a number of family members kindly gave us more in-depth detail of their care experiences received in the form of case studies. These can be seen in **Appendix 2** of this report from page 19.

7. DEMOGRAPHICS

7.1 Through our engagement we aimed to be as demographically representative as possible. Although we initially found engaging with some ethnic groups challenging, but with the support from Walsall Together partner organisations, we were able to gather intelligence from a wider ethnic cohort.

	No.	%
White British	25	61
Asian British, Indian	9	21
Asian British, Pakistani	6	15
British Polish	1	3



8. END OF LIFE / PALLIATIVE CARE: SUMMARY OF RECOMMENDATIONS

8.1 From the engagement work undertaken through the project the recommendations for improvement based on the intelligence gathered concern:

- I. Communication within the hospital staff and timely discharge arrangements
- II. Bereavement Support
- III. Accessing Continuing Healthcare funding (CHC)
- IV. Choice of Place of Death
- V. GP access

8.2 Communication with family members particularly through the pandemic when visiting was not permitted or limited.

8.3 Recommendations to flow from this engagement work follow:

i. Communication Within the Hospital Staff and Timely Discharge Arrangements

Summary of intelligence gathered:

Communication between staff and family members was highlighted as the main area for improvement. There were some comments that discussions with family members could be improved around condition management, next stages of care, and discharge arrangements. Some family members informed us that their loved one wanted to die at home or in palliative care but by the time arrangements were to be made the patients' health had deteriorated making discharge difficult.

Also, there were comments that some staff in the hospital were not having the conversations around dying. Also, where possible for staff to be able to recognise that

someone is dying sooner. This must be difficult in hospital settings, where staff can be very busy and the issue of privacy can be a barrier.

“Communication with me was poor they kept saying that he was stable in hospital and eating but I don't think they were helping him to eat. There was a lot of confusion around who should administer his medication.”

Recommendation: that there is clearer communication with family members and that the conversations when a family member of the patient is dying to be improved. It was also questioned What training is there for nurses and other health professionals around care of the dying patient?

ii. Bereavement Support

Summary of intelligence gathered:

Whilst a sizeable proportion of family members and loved ones had been offered bereavement support through the palliative care team and hospital there were inconsistencies that meant some people were not offered support or that they required bereavement support at a later date but did not know where to turn to.

Recommendation: that there is a consistent approach for offering support but that other avenues for support are made available through signposting to the offer within Walsall and national support.

iii. Accessing Continuing Healthcare Funding (CHC)

Summary of intelligence gathered:

Accessing continuing healthcare packages have in some cases been a challenge for patients and family members as noted in this report. Getting the appropriate and timely care package where possible is essential.

Recommendation: that the CHC process is sped up for those wishing to have their care at home and when the patient is coming towards the later stages of end of life, and that the later stages of end of life are recognised sooner.

iv. Choice of Place of Death

Summary of intelligence gathered:

Of the 31 people that completed the survey and through telephone conversations 11 people highlighted that their loved one / family member did not pass away in their preferred place to die.

All but one of the 11 responses relating to the place of death not being the choice were where the patient had died in hospital. The reasons for this though are varied:

- That the person was too ill to be transported and that the family members were advised that it was best for the person to stay in hospital.
- Delayed transfer from hospital to either home or palliative care.
- CHC funding delays meant that adequate care could not be provided in time.
- The patient had died or quickly deteriorated in hospital.

Some of the comments made by family members:

“When my wife went into hospital there was no suggestion of her not coming out. On the Friday before she died the nurses said she would be discharged by the middle of the next week. Blood clot struck suddenly, and she passed away within 5 minutes.”

“We were told by the doctor and hospital palliative care nurse. We were given the chance to discuss options and wanted to get mom home. However, doctor told us she would not make transfer, so we made the decision to keep in the hospital.”

“Difficult to judge where my mother would have chosen to die because she had advanced dementia, but earlier discussions indicated this was probably not the place she would have chosen. It was not the place I would have chosen for her either and there was an advanced care plan in place but due to some unexpected changes in her condition she was transferred to hospital.”

“Ok, so my mom was very poorly, and it was the bank holiday weekend, May 2021. She was deteriorating rapidly and to be honest a lot of it is a blur, however, the palliative team based at the hospital were incredibly supportive. She had a driver fitted. Mom said to me that if she went into hospital, she did not want to die in there. During those last few days, the palliative team said that she was too poorly and would probably not even make the journey home and I was allowed to stay with her. She had the best care from all ward staff, her doctor was very empathetic. I asked about mom coming home and he said that she was very poorly and would need a driver for anticipatory drugs, but that if that were our wish, he would support it. I could clearly see that she had not got long to live, so I stayed and talked to her, reassured her, and played her fave Abba music and wet her lips with her fave tippie 'stella'. Again, the staff were incredibly supportive and provided the best care all round for my mom.”

“Due to issues with getting CHC funding in place our client (from Bethphage) was sent to the palliative care centre extremely late, and she passed away at the palliative care centre very soon after she arrived.”

9. ENGAGEMENT SURVEY DATA ANALYSIS

9.1 Were you or your family advised by medical/nursing staff?

11 people informed us that there were not advised by medical or nursing staff, and that communication with the family had been poor.

“I was asked whether I wished, or whether my wife would wish, to be resuscitated in the event of her heart failing, with some outline of what the possible outcomes might be it was confusing for me.”

“Not at the beginning but right at the end, nursing staff were being vague, but we asked direct questions and then they were being direct that xxx will not be improving and was a waiting game.”

“At no point did any such discussions take place.”

“My husband health was deteriorating up to May 2021 when he passed away. It was like dementia he was getting forgetful, lack of speech and abusive. This was not my husband. We had care coming but we were not told that he was going to die soon, and it came as a shock. I asked the palliative care nurse if he was going to die to be told yes.”

“Due to the continued reduction in his steroid doses, by the time I discovered there was no plan to reinstate them or have a head scan, my brother was struggling to stay conscious. We were not communicated well at the hospital and when it came to discharge it was confusing being told different things by nurses and consultants.”

“No for support for me. This was disappointing as being a remote carer and unable to visit due to covid made it hard. I appreciate it was difficult though, but it will take a long time for me to recover from his loss. The care home was as supportive as they could be with phone calls. My Mom is also now EOL, and we are having a similar level of good care for her. We have not had support for the family - it is a bit different as she is 97 but a loss is a loss. Fortunately, we have been able to visit Mom in recent weeks.”

“Not really, in the circumstances which prevailed at the time (namely, Covid) it was extremely difficult to obtain support.”

In asking **Did you know how to access the local teams and services?** 6 people informed us that they did not know how to access the local teams.

9.2 What worked well? e.g., medication/pain management, staff ...

From the responses that we received around what had worked well there were a number of positive comments around pain management and access and reviews of medication.

We also received a number of positive comments around the compassionate, caring, flexible and timely care received from the palliative care team and the efficiency of the Occupational Therapist Assessment Team. There were several comments that the palliative care team:

- Made every effort to keep the family informed.
- The staff responded quickly and professionally.
- Palliative care staff were able to visit patients at the weekend and during night and early morning hours in time of need.
- Palliative care staff offered bereavement support to family members.
- Occupational Therapy (OT) staff were able to get the necessary equipment and aids and adaptations in patients homes quickly and efficiently.

“Medication and pain management was excellent. Good response when my husband was distressed following his stroke. Care during his covid was excellent with nurses still seeing him for his pressure sores. The Doctor rang me and was kind and professional about what should happen to him. Emergency team responded quickly to care home staff calling when he needed sedating and pain control. I passionately believe this ensured a peaceful death.”

“OT from hospice was excellent and provided equipment which helped. When we rang hospice because we ran out of pads, they put some on the desk so they could be collected straight away.”

“Everything worked extremely well and everyone who cared for her was compassionate and caring. Everyone responded so quickly, especially with her pain relief.”

“Some staff were excellent at communication; others could be considered as non-communicative. Dad's pain management and medication appeared to be managed well.”

“District nurses and MacMillan nurses and Palliative OT communicated well; we had all the equipment provided very quickly. The GP provided pain management throughout, and anticipatory drugs were provided. In the last days, the D/N, Macmillan Nurse and GP worked together to administer a syringe driver. All the team were caring, responsive and supportive. We also had the support of carers which was increased in the last days once the syringe driver had been commenced. Macmillan arranged for overnight support from Marie Curie, and this was welcomed, and we received a fantastic service.”

“My stepdad’s stay at Goscote Palliative Care Centre went well - the staff seemed kind, and they were able to adjust his medication so that he was in less pain. We were also given equipment to support my stepdad at home in a timely way.”

“Weekly phone calls from Palliative Care team. The care given in the hospice was very caring and compassionate.”

“Mom was put on a lot of medication from the hospital which was making her feel ill. The GP said that she was palliative and end of life and agreed to stop the medication. In March mom had another fall and the ambulance was called. We agreed that mom would not be taken to hospital which was her choice. The palliative care team on a Sunday came out and prescribed morphine and we were given a comfort box.”

“Equipment and OT assessment was supportive and quick to deliver equipment. Mark from palliative care team sorted nursing home and transport quickly, was compassionate and supported. Communicated really well. Team at Richmond House were lovely and caring.”

9.3. What could have been improved?

From the experiences gathered from family members key areas that have been highlighted that family members would like to see improved within the care pathways include:

Bereavement Support

Losing a loved one is an exceedingly tough time for people and accessing or being offered bereavement support is important. Some family members informed us that they had not been offered any bereavement support or knowing who to contact if necessary.

Financial Advice and Access to Benefits

We were informed that some patients and family members for those who are of working age have found it exceedingly difficult to get access to financial support when a loved one is dying. Whilst only a few people commented regarding access it was identified that getting support outside of the clinical system was challenging.

“Made to feel like we were nuisances and time wasters. Almost like they were making us feel like well you are dying anyway why are you bothering us! No individual care plan actioned no pain management no symptom controls no psychological, social or spiritual support. Absolutely no support for the family during or after. Shocking service they basically could not be bothered. Palliative care nurse assigned ineffective. Some actual care, support, and compassion. Receiving urgent supplies and equipment for end of life took far too long to action and organise. Communication was a complete nightmare. The fact that people dying have no time to wait 8 weeks in our case for a stair lift to be fitted speaks for itself. These basic needs should take priority. Apologies for the negative feedback but can only feedback with the poor service and experience received during what was an extremely distressing time. Found the palliative and end of life care services inhumane. Palliative care might work

well on paper but unfortunately for the people it affects falls somewhat short. Improvement needs to start with getting the basics right. Get the medication and equipment out in a timely manner to the people that desperately need it. Improve communication. Some of the staff at the hospital did not seem to recognise that mom was dying.”

9.4 Communication with GP's

There were several comments from family members that support from local GPs towards end of life were limited and being able to access a GP / home visits were not available for some people when they were towards later stages of life.

*“Due to COVID the care had been hit and miss and we felt that we were making decisions on our own. The GPs were non-existent. We tried to get dad to the GP to be told use Econsult. How is an old man at 94 supposed to use Econsult? *1 This is very hard for the elderly. When dad died, we were though offered support through the palliative care team.”*

“I think when clinical staff realised that there was nothing else, they could do, one should make it clear to the family, so there is no false hope of getting better.”

“It was a shame the end of life was not recognised by the hospital sooner so that end of life care could have been provided earlier in the journey.”

“Although the hospital staff was saying everything was okay, the family could see the deterioration and maybe acknowledgement of this from the team may have helped the family.”

“The only thing I would say is the timing...the bank holiday weekend/ mom living in a different authority and all of the logistics surrounding putting a care package, etc in place to come home. However, in our case, I feel it was meant to be.”

“Before going to the hospice, my stepdad was in constant pain but struggled to have this reviewed as there were so many professionals involved and communication between departments was poor. We found it very difficult to access our GP.”

“Had to wait 1 hour at night for each call out on night of passing for drugs as only 1 member of staff now on duty covering the whole of the area. In the middle of the night watching your loved one suffering this hour feels like 2! In hospital all controlled drugs are checked by 2 nurses in community no checks. No individual care plan as stated above was given. No stand for the catheter. No mouth swabs to be able to provide mouth care.”

“Communication between organisations. Very little support from GP surgery apart from the practice nurses who were doing routine checks for another condition other than the cancer. Being able to have face-to-face appointments with consultant and GPs would have been a big improvement. Some conversation with patient and relatives about what might happen as the disease progressed.”

“We would like to see a booklet highlighting what we need to do at time of death and also what benefits people could access. It really annoyed us that she could not access benefits because I worked. Why could not this be sorted in the benefits system. People with other conditions are able to access financial support but why not me?”

“Communication between organisations. Mom was going to the GP on a regular basis with chest pains and migraines. Mom visited xxxxx GP surgery, but it took months for the GP to send Mom for a CT scan.”

*1

It would seem that e-consult forms are not always appropriate for dying patients, when often the carer for the patient needs a conversation which could be urgent, and needed in the here and now

.9.5 Conversations around ReSPECT - Recommended Summary Plan for Emergency Care and Treatment

Although it was not a question within the survey, from conversations within the End-of-Life Steering Group we decided through the telephone calls to loved ones and family members to have the conversation around ReSPECT.

Of the 12 telephone conversations undertaken all but 2 of those we talked to have the conversation with professionals. We were informed that the majority of these conversations were undertaken at the hospital and through the palliative care team.

Conversation around DNACPR, choice and place of death, wishes, arrangements were undertaken in a dignified and professional manner. Family members told us that they were happy that these conversations had taken place.

9.6 Do you have any comments to help improve Palliative and End of Life Care?

In relation to what improvements could be made to the end-of-life care pathway, professional advice in relation to what to expect towards the end of life was highlighted several times through the engagement. Some people wanted information on what changes are expected when someone deteriorates but also what and when to ask for support and advice.

Some of the comments made by family members and loved ones:

“Although Mum died outside the Borough, I feel the same points could apply to a death within the Manor. As part of a dementia care pathway, it might be helpful to raise the subject of end-of-life care before the person loses capacity.”

“I feel night service should be taken over by Palliative care nurses. To call a nurse out during the night the relatives are calling because there is a problem, and they are worried. Support and explanations would be appreciated rather than an injection and straight out again. Did call evening District Nurse service as requested by carers one evening due to issues with

catheter but felt concerns were dismissed. There is the potential for drug errors as no checks. After the passing nobody checks what medication is left in the property. The nurse takes the directive but leaves the drugs, I find this extremely worrying as could easily be abused. We were given drugs by the hospice and also duplicate by the GP. Nobody has asked me where the medication is now!"

"As soon as the medical team were aware that dad's life was drawing close, please could the staff ensure they notify the family. Have a family conference to discuss the end-of-life care."

"Better access to allied healthcare professionals. We need to be given all the information before we get to the point of no return. Information is best retained when we are not under the stress of the moment. We know that my husband's prognosis is not good. We know that it is not an exact science with a definite date on his boarding pass. It might be next week it might 15 years, but I still do not know what I am going to be expected to deal with on the latter stages, perhaps if I knew what I needed to look out for..."

"There needs to be more input from GP's particularly around pain management."

"We did not receive an overnight Marie Curie during the last few days. Although we did have a sitter overnight, but Marie Curie would have been much better and alerted the family as soon as changes occurred. The family were woken when it was too late, and she had already passed. She left immediately afterwards whereas Marie Curie would have supported through this difficult time."

9.7 Positive Points in Care Pathways

There were 10 comments that people did not feel that any changes needed to take place and the work of the palliative care team was highly recognised.

"The service is wonderful! keep doing what you're doing!"

"St Giles are fantastic."

"We were offered Bereavement support for our children. Goscote staff were amazing."

"My stepdad's stay at Goscote Palliative Care Centre went well - the staff seemed kind, and they were able to adjust his medication so that he was in less pain. We were also given equipment to support my stepdad at home in a timely way."

10.CONCLUSION

Walsall Healthwatch, patients, and family members and loved ones want to see Walsall Together commissioners and providers of health and social care, act in a demonstratable way to the intelligence provided via this report and in particular the specific recommendations given earlier.

It is only by tangible and measurable improvements made, can it be said that the principle of co-production of care pathways is being achieved in Walsall and that the words in the Walsall Together terms of reference which are based on strong partnerships and working together with service users are not just rhetoric.

We recognise that during this challenging period commissioners and providers of services have prioritised efforts to support those affected by the COVID-19 pandemic and that some developmental work around co-production will be challenging. However, based on family members and loved one experiences they have highlighted some areas where improvements to the end-of-life care pathway could be undertaken.

Whilst end of life and palliative care are an emotive subject for many, embedding the family and loved one's experiences of the care pathway is important. We recognise that this is a focused sample of people that have died in the last 18 months, however the recommendations indicate some similarities in the challenges and positive comments around care pathways.

We would like to thank Walsall Together partners for their efforts and support in promoting and helping to disseminate the engagement opportunities.

A big thank you to Sindy Dhallu (Operational Manager/Team Leader – Integrated Palliative Care Team –Nursing & AHP (acute & community) and the palliative care team.

We would also like to thank the family and loved ones for sharing their stories.

Paul Higgitt – Senior Engagement Lead, Healthwatch Walsall
Phil Griffin Walsall Together Service User Group Chairman



Appendices

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Appendix Three – EOL / Palliative care survey – page 25

Appendix One - Key Points made from family members / loved ones

We were informed that dad was dying but a plan of care was never discussed with my mum, my siblings or myself. We certainly had no idea of what was important to him, but he did tell us that he wanted the family close. My mum, siblings and I ensured we were with him during his last few days and mum, and I slept in his room beside him on his last night. This was dad's choice.

Not at all, no support at all. Shocking treatment by one ward/ consultant at Walsall Manor who sent him to a rehabilitation centre for his breathing. He was sent back immediately the next day as clearly not the correct place for him. This was not explained to my father or family.

I was told by the Doctor who was looking after mom that she was dying. She had not eaten for 2 weeks, drank very little. I had looked after my mom for many years due to her health complications, we were very close. I asked about her coming home, but I knew that she did not have long left and being a bank holiday like I said previously, meant services would not be put in place quickly. The hospital palliative team explained my mom's meds to me and how the driver worked. They gave me a 24-hour number to call and gave lots of reassurance plus they popped in regularly to see us.

We were informed on 09/06/2021 that my stepdad had about a month to live - 3 months after the cancer had initially been discovered. He had planned to spend his final days in a hospice. My stepdad had also asked to not be resuscitated.

The care planning was patchy - it was clear to us as family members that the end was near (we had previously experienced similar with another family member). But our requests for urgent support did not seem to recognise the rapid deterioration and there was a long gap between support visits. We did not have good information on what care was available nearer death, nor other options if she changed her mind.

The last few months the palliative care team stepped in and the support and care that she received was 5 star they were really supportive. Kaz at Macmillan was also very helpful in supporting us with advice around finances.

My husband had had covid, so a conversation had taken place about what care was appropriate in the circumstances and how I wanted him to be looked after. Response teams were great.

Several close family members visited to sit with mum over her last few days. It was a very stuffy, dark side room with no window to the outside and although it was private a window to look out would have been better.

More information earlier about end of life care. A member of staff to discuss the issues with close family members (mum, siblings, and myself) around his care and what we could have done.

My mom had cancer we were not informed she was end of live at no point told and we got a call one morning and we got there, and she died an hour later she was supposed to be going into a home at that point but were weren't told it was end of life when we questioned it the ward manager stated well couldn't you tell!

Not sure whether it was the cancer or the mini heart attacks that the doctor told us she was having but the ward manager said she was not, but it is in the medical notes we asked for also she fell while in the hospital, so we don't know if it was down to that as she hit her head. Could have been 100 percent better my mom died with no dignity and when we complained they did not care.

Highlighted Cause of Death

Dementia and stroke, chest infection COVID
Lung cancer - 11
Brain Tumour
Cancer other
Aspiration pneumonia and dementia
COVID - 3
Bowel cancer which spread to her liver
Sarcoma
Complications of diabetes.
Cancer of the bowel
Chimera, heart failure, COPD
He had stage 4 cancer
Age Related
Secondary breast cancer,
Renal cancer. Digestive system affected
Heart failure
Blood clot on lung
Not sure whether it was the cancer or COVID
Sepsis and Kidney Failure

Heart failure and kidney failure (newly diagnosed).
Lung cancer
Brain Tumour - Benign
Secondary breast cancer
Cancer / COVID
Cancer - other
Breast Cancer
Pancreatic cancer
The brain tumours paralysed he stopped breathing
Chest Infection and related pulmonary condition.

Note: Majority of family members highlighted that their loved one had died within the last 18months (up to September 2021).

Four of these were identified as COVID or COVID related.

Appendix Two – Patient Stories

Case Study 1

This lady who has been supported at home living for over 20 years. The lady is in her 80's and has a learning disability. The lady had mastectomy in 2019. In Nov 2020, her health started to deteriorate, and she was struggling to get support from her GP, so she was referred to the PAMS team she was being supported by the PAMS team, but she then went into isolation due to COVID. In March 2021 when she gained her first face to face appointment, the GP was not able to do a full assessment as she uses a wheelchair and the GP referred her to Walsall Manor hospital for a CT scan. The lady went into hospital relating to another matter and the CT scan was completed this highlighted secondary stage metastatic liver and bowel cancer. An MDT meeting had been held and a number of people within the MDT Team highlighted it would be in her best interest to be at home. The lady has always said that she wanted to go home but it was agreed in the meeting that she now lacked capacity. The lady was sent home in agreement by the family and providers with the caveat that she would have wrap around care until Tuesday 4th May to allow for a care package to be agreed upon. On the 7th May she was moved into Goscote for review and assessment to plan for a care package. She had been receiving Learning Disability Continuous Healthcare (CHC) funding but as she was now deemed end of life, she has been fast tracked to End of life (EOL) CHC by the Social Worker. Practitioners wanted her to go to a care home, but the family and care provider (who had supported her for 20 years) highlighted that with her learning disability, pain management, comfort, choice and as she gets confused it would be better for her to go home. Due to the CHC funding element it was becoming very difficult to get a CHC funding package that was suitable for her care needs. Even though the EOL Fastrack states there is likelihood that she could pass away with the CHC 28 days. However, over a period of a few weeks the CCG were able to make available funding to provide for a suitable care package for the lady. The lady was eventually supported home on the 19th May where she passed away on the same day. Although the lady has been heavily supported by Bethphage and a MH Advocate it has taken significant efforts for the care at home to be put in place. Key Issues In relation to the integration of health and social care CHC and local authority funding arrangements have in this case highlighted challenges within the system to provide the care choice of a patient towards end of life

Case Study 2

I am very conscious that R died at an exceedingly tough time for everyone in the care home, the NHS etc. He did have covid and the emergency response team were excellent as was the home. He did not have serious symptoms, was regularly monitored, and then had a negative swab about 6 weeks later. It seems he then had a stroke - do not know if it was covid related or not. I know the staff at the home wished they could support me better but clearly circumstances did not allow close or physical contact and I fully accept that was correct to protect the carers, the home and me.

The home manager offered that I could ring her for a chat whenever I felt the need and would send the occasional message via phone. I did ring from time to time but felt they had enough to deal with in this most difficult of times. In different circumstances I know I would have been welcome to visit for a cup of tea and a chat but clearly that was not to be. I will visit when circumstances allow. I do not recall anyone offering any bereavement counselling.

I realised recently that I was surprised that no-one from the GP surgery had made contact with me following Rick's death. They had rung following his covid diagnosis and were kind and professional discussing how he would be best cared for. I understood his EOL diagnosis and what support was in place for that which was comforting - knowing he would not be distressed or in pain helps a lot. They responded well when I contacted them about the EOL situation albeit that an admin error occurred - they apologised, and I agree it made no difference to his care as the emergency response team did everything needed.

I really do not want to sound selfish and understand fully the current difficulties in supporting the sadly many people who have lost someone in the current situation but having been Rick's carer since his initial Alzheimer's diagnosis in 2014 I had been slowly losing him all that time. Living grief, living bereavement. My GP did refer me to WPH for talking therapy when Rick went into care which was useful - he went into care July 2017, my therapy was April 2018

Carers need support throughout the caring process from the diagnosis of their loved one's terminal diagnosis up to and after death. The support needs to be two-fold - firstly someone who can help navigate the complexities of the system from a practical viewpoint - what help is available, who do you phone regarding a or b, financial advice, etc. - an advocate or a navigator. Secondly on a personal level - how is the carer coping, how do they feel, what will help them get through this and enable them to continue to care - and then support after the death to cope with the loss not just of their loved one but also the loss of purpose in their life, where do they go from here, how to not drift (unless they want to), how to find purpose as well as practical support that may be needed - signposting perhaps to benefits, finding a job etc.

If someone had rung me in the first few weeks after R's death, they would have thought I was fine - busy with paperwork, organising etc. which I managed just fine - I worked for the Co-op so knew the staff there - so it's not just one phone call that's needed, it's followed ups for a few months after - ideally with in person meetings either one to one or in bereavement groups.

I am a member of TIDE - Together in Dementia Everyday - it is a charity that supports dementia carers sadly not active in this part of England yet but active in Scotland, Wales, Northern Ireland, and the north of England. I have been to conferences with them and been involved in meetings and research for them. These have ended for now, but we do zoom based coffee mornings for carers, and a monthly one for former carers - they also offer zoom based short courses. I have found these coffee mornings useful. Are there any local groups doing this? If so, I could have been put in touch. I can google of course but there is nothing like being personally introduced, welcomed, or guided to the group that may suit my situation best. Does the GP surgery run a carers group? A bereavement groups. I do not know. One to one bereavement support is also needed for more personal support.

I know I can ask (my GP?) and perhaps I should have but it is so much better to be asked, offered help, and followed up - not chased of course as it is not for everyone, but carers can also help each other in groups - even if it is just a laugh and a few tears over a cup of tea.

Sorry if I have rambled on (I know I do) but I did want to put some context around my comments and I am more than happy to discuss this further if it helps.

Case Study 3

Mom passed away on the 9th of May 2021 at our home which was her wish and choice. Mom was diagnosed with lung cancer in November 2020. This was diagnosed at stage 4. Mom did receive one dose of Chemo at Walsall Manor however she had severe side effects and the cancer was aggressive, thus it was agreed not to undergo further treatment options.

Mom had worked in Walsall Healthcare NHS Trust for over 25 years. Mom was admitted into hospital early this year and I can only say that at first the general treatment and care was dreadful. Mom was in significant pain, and they were not able to control her pain management. On reflection we were in lockdown, but it took 4 days for me to get through to the team and discuss my mom's care. At one point mom could not swallow well and asked for a glass of cold water, later to be given a jug of warm water. Fundamental basic care.

Her cancer care needed to be speeded up as she was uncomfortable. Mom was referred over to the cancer team at the hospital and we were supported by a Senior Cancer Nurse where mom was put on a syringe driver. The care was then extremely good and even the Senior Oncologist from QE was able to see mom.

When mom was discharged, we picked her up and went home. She does not have a downstairs toilet or bed and we were not made aware of aids and adaptations.

Mom was in agony and a District Nurse arranged for mom to be admitted into Goscote for 10 days. The quality of care at Goscote was amazing and they were able to manage her pain.

The Occupational Therapists were also able to get a commode and bed for downstairs at her home. Mom was in so much pain in her chest and we were informed that this could have been due to complications or fractures in her Sternum which was not picked up at hospital.

When mom was at home, she also received an oxygen support machine as her breathing deteriorated.

Mom and the family had a discussion with the District Nurse around RESPECT where we discussed mom's quality of life, signs of deterioration and who we wanted to be involved in her care and her wishes.

A CHC package of care was put in place.

At home mom started to receive private care through (xxxxxx), Walsall. The care initially seemed to be ok, but it was made categorically clear that the 2-person care which was from 10pm to 7am that both staff members must stay awake.

There were several times that my mom said both staff had made themselves comfortable and went to sleep. They also had headphones on. I as her daughter also witnessed this and complained to the company.

Mom was persistently woken up with snoring, and she was so frightened as she did not want to have her last breath with no one around her, that it was she feared most.

We built up a relationship with one of the carers and she was like a family member. One morning she told us that she was having to raise a concern as her colleague said I am going to turn off the oxygen machine because of the noise to which she was told by her colleague that if she did this the Police would be called. We were informed that the company would be taking this very seriously.

As mom could not now use the commode, the District Nurses explained that mom needed to be doubled up. Several times I found my mom's bed soaking wet with urine and I had to clean her. At one point the care staff had administered medication three times the required dose to which the District Nurse was shocked.

Mom built up a great relationship with the Palliative care team and District nurses and she would talk to them how care was delivered many years ago. Mom was an immensely proud woman who would also keep clean and tidy.

When mom passed away, we were able to dress her in her nice pyjamas which she wanted. The District Nurse helped me clean mom and dress her which was very comforting. We were also offered bereavement support through the palliative care team.

Mom passed peacefully with her close family around her.

We would like to thank EW, MP and CH from the hospital palliative care team that came out to see mom even at weekends and in times of need and for the care she received at the palliative care centre.

Words of LK's daughter.

The daughter has been grieving and was at the time not in the best place to raise the concerns in this case study. She has now raised these with us. We have passed the details on to the CHC Lead and the Director of Adult Social Care.

Note – the issues raised in this case study from the family have been escalated to Senior Management level within Walsall Healthcare NHS Trust.

Case Study 4

Dad always had the wish to die at home. He had prostate and bowel cancer. He had been bed bound since November 2019. He received four care visits a day. But me and my brother were his main carers. District nurses checked on him every 3 months. The palliative care did dwindle off until the last few days in which dad said he was in pain and the palliative care team stepped in and gave him a syringe driver. The speed of the palliative care team getting involved towards the end was very quick.

We were told and discussed RESPECT and it was always agreed that a DNACPR would be in place. An ambulance came once but we told them that there was a DNACPR form in place.

It was easy to access the palliative care team. We were also provided with Nutricream from the hospital as my dad could not swallow very well.

Due to COVID the care had been hit and miss and we felt that we were making decisions on our own. The GPs were non-existent. We tried to get dad to the GP to be told use Econsult. How is an old man at 94 supposed to use Econsult? This is very hard for the elderly. When dad died, we were though offered support through the palliative care team. This was very reassuring and caring.

Dad passed away at home which was his choice.

Case Study 5

My wife was diagnosed with breast cancer 14 years ago at the age of forty. She underwent an array of chemo and treatment, but it had returned as secondary cancer a few years ago in her liver and lungs. She passed away in May 2021. The dedication of the chemo department at the hospital was really good. We were told that it was terminal the last 2 months before she passed away. My wife did get aids and adaptations at home, and they helped with the new layout of the house which was good. Until March we were not offered any help at all. When we did get support, we had the district nurse come in times but only for 10mins and there were no physical examinations done. The Palliative Care Team discussed the RESPECT form with us, and we signed DNACPR

The last few months the palliative care team stepped in and the support and care that she received was 5 star they were really supportive. Kaz at Macmillan was also very helpful in supporting us with advice finances.

It was very difficult at the weekends. When my wife had to go into hospital there was very little cancer service provision. She could have been put anywhere ward 29, 14, 15 and not always in a side wardroom. There is no dedicated unit at night or weekends. It also took time to get pain relief as my wife's stomach had swollen. My wife several times tried to get a GP appointment at Rushall Medical Practice. Even though we explained that she had cancer we could not get a face-to-face appointment. No GP home visits available and when we requested prescriptions there were things missing on several occasions. We would like to see a booklet highlighting what we need to do at time of death and what benefits people could access. It really annoyed us that she could not access benefits because I worked. Why could not this be sorted in the benefits system. People with other conditions are able to access financial support but why not me?

The support from the discharge team was very hit and miss until the Palliative Care Team were involved.

Case Study 6

Mom was seventy-eight and was suffering from a bad chest infection and was eventually diagnosed through a Bronchoscopy. Mom spent 2 weeks in hospital and was then discharged. Mom was not eating at home. In March 2021 Mom's asthma was getting worse and we requested a GP home visit which was declined. No one would come out to see her. In April 2021 mom was admitted back into hospital. No one was allowed to go and see her. We were informed through the palliative care team that mom was End of Life, and that they were increasing her oxygen. We phoned daily but they did not always get back to us or keep us informed. We know they were busy but when your mom is end of life it is important for people to keep you informed. In the 2nd week we were told to go up to the hospital as we were informed that she may not make it through the day. Mom was admitted to ICU. Mom spoke Gujarati which meant that she couldn't communicate very well. However, there was a nurse who spoke Gujarati on the ICU ward. We discussed with Doctors about switching off the ventilator as she was unconscious and now being kept alive by machines. We couldn't speak to mom, and we were not kept informed regularly as she deteriorated, and this was very upsetting. We did discuss RESPECT but Mom's wish to die at home was not possible. Mom was kept comfortable with oxygen and sedatives. Communication with us was however poor. We know that COVID had been an issue and we would have preferred for mom to die at home. It has not been easy but what has made it worse has been judgement calls from the hospital to decline us from seeing mom. Mom seemed to be losing weight and we don't think enough time and effort was made to feed her. Why couldn't we do lateral flow tests so that we could see mom.

Case Study 7

Dad passed away aged 55 on the 2nd of September 2021 from Lung Cancer. Dad was having immune therapy but started to deteriorate in June 2021. Dad was having regular visits to the hospital, but we were soon in discussion around palliative care. When Dad went to the hospice, we were informed about Dad's care, discussed his wishes and the family were told

that they could go and see him at any time. The Palliative care centre were able to manage his pain in his legs and stomach. Once Dad had passed as he was Muslim, we were supported to wash him and for him to be moved for burial quickly as part of tradition. The Palliative Care centre were also able to help us make arrangements with the Mosque. The Palliative Care Team also kept us informed and were very supportive with the family. During the early stages of the pandemic, we couldn't get a GP appointment for Dad and without a face-to-face appointment Dad did not get referred quick enough to the hospital to start treatment.

Case Study 8

Mom died on the 11th of July 2021 from Lung Cancer. Mom spent one day in the hospice, but all the arrangements were put in place to allow mom to come home to spend her remaining time here. Mom was going to the GP on a regular basis with chest pains and migraines. Mom visited xxxxx GP surgery, but it took months for the GP to send Mom for a CT scan. From December mom did receive Chemo but the cancer had advanced. Due to COVID we were not able to visit, and translation was problematic as she couldn't explain pain and her needs. When mom deteriorated the hospital were not forthcoming in telling us that mom was dying and to be prepared. However, towards the end stages the Palliative Care Team at the hospice were able to arrange a carer 2-3 times a day which was good. They were also offered the family support. The worst had been the times that the GP dismissed it. We are Polish and my mom was Catholic, and the Palliative Care Team were able to support in arranging a Priest and help us with the funeral arrangements.

It took a long time for the hospital to have the conversation with us about end of life. The Palliative Care Team were very comforting, and we were well communicated.

The Palliative Care Teams Response getting care in place, communication and empathy was very good. We should have though had a better response from the GP who dismissed my mom's condition as a chest infection

Case Study 9

Son – Punjabi speaking, translated through Healthwatch Leicester staff member.

Mom passed away 13th May 2021 aged 73. she passed away from COVID-19. Mom died in Walsall Manor Hospital. She was diabetic but no other health conditions. We were allowed to speak to mom through the phone, but we were not allowed to see her when she passed away. When mom first went to hospital, she was on the COVID ward but was transferred to another ward when she was getting worse. We went to hospital to change moms' clothes and ask to see mom they did allow us to but the last few days the hospital did not communicate with us. We were not allowed to see her. 1 day before she passed away, we received a phone call to say mom had fallen over in the bathroom and her oxygen levels fell very low. We were informed that mom wanted to go to the bathroom herself. When she

passed away staff were very sympathetic. The hospital did not offer any support to talk to someone after mom had passed away. When we went home, we received a phone call 3 days after from the hospital sending us their condolences.

Appendix Three – EOL / Palliative care survey

End of Life Experience Questionnaire

We would very much like to learn about your experiences of the 18 months of life and experiences of end-of-life care services. Our aim is for all Adults, Children and Young People at End of Life to be supported to achieve their ambitions as identified through the care planning process.

This questionnaire relates to any experiences in the last 18 months both before and during the Coronavirus pandemic.

This listening exercise will run for (fill in dates/weeks) and close on 21.

We appreciate you taking time to help us monitor and improve our care delivered to all in the last 18 months of life in Walsall.

1. About you:

Are you a carer / family member / other relationship to person close to you [multiple choice question]?

Other (please advise) – [Free text box]

2. About the Care Received

2a.

Was the care of the person close to you received at:

home

hospital

hospice

Other location? Please advise.

[free text box]

Please advise name of hospital or hospice.

[free text box]

2b.

Where did your relative (person close to you) die?

At individual home

Residential or Care Home

Hospice

Hospital

Was this their preferred place?

Yes

No

If no, could you please provide more details?

[free text box]

3a. Care Plans for Patients

Were you or your family advised by medical / nursing staff or other healthcare professional that the person close to you was dying, given the opportunity to talk about a plan of care with the person close to you and what was important to them?

Yes / No

Can you please explain why you have answered Yes or No to the previous question?

[free text box]

3b.

Did you know how to access local information and outreach support during the palliative/end of life journey for the person close to you?

[free text box]

An individual's plan of care is agreed with the patient / those close to the patient, coordinated and delivered with compassion (including food and drink, symptom control, psychological, social, and spiritual support).

End of life care aims to support someone in the later stages of a life-limiting condition to live as well as possible until they die. It also aims to support family and carers during this time and after the person dies.

4a. What worked well?

E.g., Medication / pain management, staff care, communication, between organisations, access to timely equipment etc.

[free text box]



4b. Could have been better?

[free text box]

5. Additional Feedback

Do you have any comments to help improve Palliative & End of Life Care delivered across Walsall across the hospital, community including GP's, at home, care home or hospice?

[free text box]

6. Ethnicity Monitoring Questions

Please could you advise the first 3 characters of your post code e.g., WS2?

Male / Female / Prefer not to say.

Age

Ethnic Origin

Religion