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Dorothy House Hospice Care User Advisory Group:

a year of supporting patient and carer
involvement

**An
independent
voice for the
people of
Wiltshire**

DOROTHY
HOUSE
Hospice Care



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Dorothy House Hospice Care User Advisory Group: a year of supporting patient and carer involvement



Background

Dorothy House Hospice Care supports people with a life-limiting illness across a large geographical area which includes Bath and north-east Somerset, part of Wiltshire and part of Somerset. Care and support is given at home, in the hospice or at one of their outreach centres.

Healthwatch Wiltshire is the county's independent health and care champion. It exists to ensure that people are at the heart of care. Dedicated teams of staff and volunteers listen to what people like about local health services, and what could be improved. These views are then shared with the decision-making organisations, so together a real difference can be made. Healthwatch Wiltshire can also help people find the information they need about health and care services in their area.

The Healthwatch Wiltshire service is run by Evolving Communities CIC, a community interest company limited by guarantee and run by a Board of Directors who are responsible for its strategy and overall management.



Overview

Dorothy House Hospice Care asked Healthwatch Wiltshire to establish and maintain a user advisory group to support user involvement in service development and quality monitoring of Dorothy House Hospice Care services.

Dorothy House Hospice Care is committed to involving and consulting people who use their services to ensure that this process is integral to the services they provide. Healthwatch Wiltshire exists to promote user involvement in service development and quality monitoring and can provide independent scrutiny.

The User Advisory Group was established in September 2016 and is a forum where engagement and discussion of people's views, comments and ideas can take place on the care and support provided by Dorothy House Hospice Care.

The aim of the User Advisory Group is to provide an opportunity for those people who have used Dorothy House Hospice Care services (this includes patients and/or their family members and unpaid carers, general health and care service users, those interested in end of life care and those interested in promoting the voice of users more generally) to express their open and honest opinions.

The outcome of its discussions will be used to influence service development, enhance the quality of services and promote community engagement.

What we heard: *key messages*

Through discussions at the User Advisory Group meetings and through talking directly to patients, families and unpaid carers we heard:

- Dorothy House's services are highly valued by patients, their families and carers, but more awareness and understanding of the range of services that Dorothy House provides is needed.
- That at the point of referral, patients want to talk to skilled staff with the time to support them in a personal way.
- About the importance of listening to patients and their families and carers so that care. is led by them
- That there needs to be equal access to services across geographical boundaries, and that these services are available at times to suit different individuals.
- About the importance of joined-up working with other organisations and a better use of technology.

The User Advisory Group questioned whether the extensive range of high quality services provided by Dorothy House was sustainable in the long term if patient numbers increase.

What we did

The User Advisory Group is now a well-established and supported group with a greater understanding of Dorothy House Hospice Care and the support that it offers to patients and their families and carers. Activity to date includes:

- Project Officer recruited, DBS checked and trained.
- 12 volunteers recruited (currently from Wiltshire and BaNES), DBS checked and trained.
- The User Advisory Group has met 8 times.
- The User Advisory Group has carried out direct engagement sessions with 53 Dorothy House patients and carers.
- Volunteers have attended 7 different groups to engage with service users.
- Volunteers have engaged with 7 community teams.
- The User Advisory Group has commented or directly engaged on the new Single Point of Access project, the draft *Carer and Family Strategy*, Wiltshire's draft *End of Life Care Strategy*, Dorothy House's User Involvement Statement of Intent, the Patient Experience of Care questionnaire project, the Nurse Specialist service review, medical appraisal and revalidation.
- The User Advisory Group has evaluated their input over the year.
- Four reports have been shared with the Dorothy House Hospice Care Governance Committee.
- Flyers produced to advertise the group to patients and carers.

User Advisory Group has had a wider involvement with the work of Dorothy House, undertaking the patient-led assessment of the care environment in June and joining a Single Point of Access sub-group.

Themes

1. Single Point of Access

Dorothy House's Chris Krajniewski and Becky Avery introduced the User Advisory Group to the new Single Point of Access project. Dorothy House wanted the group to comment on what is important to patients and families when they first make contact with the Dorothy House Hospice Care. This will be taken into account in the design of the new Single Point of Access from the outset.



“Some patients who had no prior experience of Dorothy House told us that they felt apprehensive about being referred there. Once they started accessing services they felt reassured.”

“Being on the User Advisory Group has shown me that Dorothy House Hospice Care is about living well with a range of conditions, not just cancer.”

Some of the key points from the User Advisory Group members considering the Single Point of Access were:

- The Single Point of Access needs to be technically well-structured and kept up to date to support patients effectively.
- Staff should have the skills and information to give the needed response with one phone call.
- Callers need to feel staff can give them time and reassurance; this builds trust into the service.
- Staff should be aware that some callers may have no prior knowledge of Dorothy House’s services.
- Staff need to enable patients to continually access the services they need throughout their time under Dorothy House’s care.
- The access point needs to be available outside normal working hours.
- It should be a personalised service that takes carers’ needs into account.



User Advisory Group volunteers also engaged with patients and families by attending the COPE Course, Time Out for You, the day patient unit and the Sewing Bee. They drafted a set of questions about people's first contacts with Dorothy House. A summary of this feedback is in Appendix 1.

IMPACT - The User Advisory Group has fed into the early design of the Single Point of Access project by giving a lay perspective and through patient and family engagement. The Group will continue to monitor the development of this ongoing project.

2. Draft Carer and Family Strategy

Dorothy House's Susanna Watson gave the User Advisory Group an overview of the draft strategy and sought their views on several aspects including the support carers and families need and how to identify and assess their needs.

The outcomes of the User Advisory Group discussion were fed back in writing to Susanna Watson and included the following points:

- It is important for carers and families to be heard - to be asked, 'What would help you at the moment?'
- A joined-up approach with other agencies saves resources and makes it easier for carers and families to access services.
- Equality of access to services, regardless of geography.
- The right level of support to be given at the right time and 'over supporting' avoided. Sometimes families feel their privacy and 'home' being taken away, particularly if equipment is needed at home.
- Enable people of working age and those at school or college access to groups at appropriate times of day.

"The User Advisory Group has given patients, families and carers the opportunity to be a 'critical friend'."

IMPACT- When Susanna shared the final version of the strategy with the group she said:

“I found the feedback I received from the group very helpful and hope that people will see that many of the comments and views have found their way into the final version... when I presented the draft to the group, they had some very robust things to say about the whole language around ‘assessments’ and ‘eligibility’...it reminded me just how easy it is to slip into bureaucratic jargon when you work in a health or social care setting.”

3. University of Oxford, Patient Experience of Care questionnaire project

Dorothy House's Ruth Gretton explained that Dorothy House was part of a pilot project testing the use of a patient experience of care questionnaire. The questionnaire has been developed to capture experiences of care and inform service improvement. Ruth wanted the User Advisory Group to provide a user perspective on the questionnaire content and governance of the distribution and completion of the form. This will feed into Dorothy House's response to the University of Oxford at the end of the project.

The group highlighted the following:

- The definition of ‘care team’ needs to be open ended to allow the patient to express what that term means to them.
- Some people, for physical or cognitive reasons, would not be able to fill in the form for themselves. The group offered some solutions to this.
- The content of the accompanying letter to patients was key to getting the best response to the questionnaire and the group identified points to be included in the letter.

This project will be complete in the autumn and Ruth will attend a meeting to discuss the outcomes and reflect on its impact.

4. Nurse Specialist Review

Dorothy House is undertaking a review of its Nurse Specialist service and wanted the User Advisory Group to speak to patients, their families and carers about their experiences of using the service. The responses would help shape the Nurse Specialist service in the future. They also wanted the group to engage with community teams, which they did by telephone.

The group engaged with 30 patients and families and 7 community teams both face-to-face and by telephone. A set of questions were drawn up in consultation with Dorothy House's Derek MacPhail. Volunteers spoke to people at Tea@3, the carers' course and Coffee Club as well as to patients and community teams (all contacts were supplied by Dorothy House).

A summary of the responses is in Appendix 2, and these together with detailed feedback have been shared and discussed with Dorothy House. Our key findings were:

- The service is highly valued by patients and families; comments were overwhelmingly positive.
- Some people wished they could have had an earlier introduction to Dorothy House.
- People valued the time given to explore their needs and felt included and supported in decision-making.
- Most people were unsure whether they would use the service if it was available 7 days a week; they had emergency numbers and felt that they had weekend cover if they needed it.

IMPACT - “The User Advisory Group’s engagement work has had a big impact on the Nurse Specialist Review. It has demonstrated a higher level of satisfaction than expected and that this will prompt a radical rethink on our approach to the Review.”

Derek McPhail, Community and Outreach Team Manager

5. Other Topics

The User Advisory Group also discussed Dorothy House Hospice Care’s mission and values statements, its User Involvement Statement of Intent and medical revalidation, as well as receiving an update from Dorothy House’s Steve Dale on community partnerships.

Evaluating the User Advisory Group

The User Advisory Group and Dorothy House carried out a period of reflection and learning following the work of the group over the year.

They reflected that:

- The group has developed its understanding of the services offered by Dorothy House and has offered an independent user perspective on a range of topics.
- Through directly engaging with service users, the group has provided Dorothy House with evidence of the impact of their services and of how Dorothy House is perceived generally in the wider community.
- The group felt that communication links between the User Advisory Group and Dorothy House are strong and they had worked well together.

“We have had the opportunity to have a dialogue with Dorothy House staff when they have presented to us.”

- The User Advisory Group has appreciated the time given by Dorothy House staff to present topics to the group, which enabled informed, productive discussions.
- It has been beneficial for the group to hear how their comments together with patient feedback have influenced service delivery.
- The two engagement periods have been a learning experience. The group needs to ensure that volunteer resources are used effectively and that activities are focused to ensure that the group delivers high quality feedback to Dorothy House.
- The group must keep the user perspective on palliative care at the centre of all discussions.
- The group has offered a ‘fresh pair of eyes’ and helped Dorothy House develop its services in ways that work for the people that use them.
- The group’s engagement activities has given patients and families the opportunity to be consulted independently and have their needs met.

Next steps

The User Advisory Group will continue into 2018 and will work with Dorothy House and Healthwatch Wiltshire to ensure the views of patients, families and their carers are reflected in the design and development of services provided by Dorothy House.

A work and engagement plan for the next year is included in Appendix 3. This includes feedback from Dorothy House to show user advisory group members the impact it is having.

We will continue to raise awareness of the User Advisory Group among Dorothy House staff and service users. A new flyer will be designed for distribution and included on the Dorothy House and Healthwatch Wiltshire websites.



Appendix 1

User Advisory Group Engagement Single

Point of Access Responses

Key Points:

Responses from 21 patients and 3 carers



Who referred you?	Some people couldn't remember or were unsure, other responses included GP, OT, COPD team, District Nurse, Impact Team
How did you feel about this?	Most people were apprehensive initially but are now very glad they were referred. UAG volunteers felt this related to the perception of Dorothy House as a 'place to die'. One carer was very unhappy that they had to ask their GP for a referral having heard about DH from a friend.
Did you understand why you were referred?	There were two 'no's', but everyone else understood although some needed a third party to explain it to them.
How long between referral and first contact?	It was up to a couple of weeks for most people who were happy with that. Three people had to wait over a month and on two occasions this was due to faults in a new referral system.
What services were you made aware of on first contact with DH?	Most people seemed to be directed to the service that was best for them at the time, eg COPE course, Day Patient Unit. One person felt overwhelmed by the information but most commented that it was the right amount of information at the right time.
What were you hoping for from your first contact with DH?	Support for patient and family, companionship, a chance for their illness to go to the back of their mind. Some people didn't know what to expect so couldn't answer the second part of the question (below).
Did it meet your expectations?	13 patients said yes. No negative responses.
What would have made your first contact better?	Most people felt that nothing could have made it better. Three people would have liked it to have been sooner (they had all waited up to several months).
What do you think is important for families and carers of DH patients?	We only spoke to two carers who said they valued the support, not being made to feel silly, being included. One person particularly appreciated the practical help with finances and forms. Patients felt support and an opportunity for their carer to have a break was important as was knowing that the patient was well looked after and in good hands at DH. They also valued the knowledge and information they could obtain from DH.
Any other comments?	Comments were overwhelmingly positive with high praise for staff and volunteers. People felt that everyone had time for patients and their families and took nothing for granted. They were disappointed if they had to miss a session. The food was praised on several occasions although a vegetarian patient mentioned that it sometimes wasn't so good. One person mentioned difficulty reaching soap and towels in the disabled toilet (needs to be at waist height).

Appendix 2

User Advisory Group engagement feedback from patients and families, July 2017 Nurse Specialist Service

<p>We spoke to 13 patients, 13 family members who had been bereaved and 4 people who are caring for a Dorothy House patient</p>	
<p>How long have you had contact with the Nurse Specialist Service?</p>	<p>This ranged from one week to over 2 years, with the majority receiving the service for several months. For some people it was 2 - 3 years ago so difficult for them to remember.</p>
<p>Did you understand the role of the NS compared with the GP/ District Nurse?</p>	<p>Most people answered 'yes' and saw a clear difference in the NS service. Some people didn't initially realise what or how much the NS could do to help them. One or two people knew they were Dorothy House patients but were a bit unsure who was who from DH.</p>
<p>What works/worked well and what would you improve?</p>	<p>Most people felt there was nothing that could improve this excellent service. Having a single, accessible point of contact for the patient and their family was important to people, as was help with pain control and practical matters like Blue Badge applications. The NS 'gets things done'. One patient found it a bit difficult to work out who was who and some people wished they could have had an earlier introduction to Dorothy House.</p>
<p>Were you given enough time to explore your needs/ encouraged to ask questions?</p>	<p>People felt the NS always had enough time for them (both patients and families). Several carers said they valued the rapport the NS had with the patient which meant that difficult questions could be asked and they knew their questions would always be answered. One carer would have liked the opportunity to speak privately with the NS, but couldn't remember having had this (several years ago).</p>
<p>Was the service responsive to your needs and were you given enough information?</p>	<p>Everyone felt they had enough information. They found the service responsive, phone calls always returned and patients looked forward to the NS visiting. One person said the uncertainty about availability of a bed for his loved one at the end of her life was difficult. Several people said that the Carers' Course and the bereavement support have been a great help, and Tea @ 3 and Coffee Club were highly valued.</p>
<p>Did you feel involved in the decision-making?</p>	<p>Everyone answered 'yes'. People felt their wishes were respected and that options were clearly explained to them without being 'told what to do'. For some people the illness was very short so there was little decision-making involved, but they were glad that their loved one was able to die in their place of choice.</p>
<p>If the service was available 7 days a week would you use that opportunity?</p>	<p>5 people said yes, 5 people said no and the remainder were unsure. Most people said they had a list of emergency numbers and felt they have cover at the weekends if they needed it. Some people said they wouldn't need 7-day cover at the moment, but might need it in the future.</p>

Appendix 3

Task	Outcome	Lead Lise Griffiths	Responsible Lucie Woodruff	Notes	Time frame
1. Review and Evaluation of year 1					
Work with Dorothy House and group volunteers to assess and evaluate the project. Produce a year 1 report and evaluation Present to the Clinical Governance Committee	Dorothy House and Healthwatch Wiltshire can illustrate the impact of including patient experience in the development of services				Sept 17
2. User Advisory Group meetings and engagement activity					
Day to day support to volunteers Schedule 12 meeting across the year identifying the most appropriate time to include engagement activity Book and arrange venues and speakers for meetings Communicate date and venues for the meeting to volunteers Manage volunteer attendance and hours and liaise with HW Volunteer Involvement Officer Provide appropriate papers to volunteers prior to meetings Collate and compile all feedback from each meeting and share with volunteers and DH	Dorothy House UAG members are <ul style="list-style-type: none"> supported well well informed able to make a contribution have the tools they need to support engagement offering patients, carers and others the opportunity to share their experiences Dorothy House <ul style="list-style-type: none"> realises its aspiration of patient and public engagement and involvement develops its services using the voice of its users 				Sept 17 - Aug 18
3. Report to Clinical Governance Committee					
Produce a quarterly report for the Clinical Governance Committee Attend and present report when required	The voice of patients, carers and the public is amplified to the people who make decisions about services				Quarterly
4. Communication					
Work with Healthwatch Wiltshire and Dorothy House to publicise group, its role and all meeting and engagement dates	The work of Dorothy House, Healthwatch Wiltshire and the UAG is promoted throughout the networks of Wiltshire. More people are offered the opportunity to share their views and experiences with the UAG. More people are offered the opportunity to be involved with the UAG				Sept 17 Feb 18
5. Review					
Complete an evaluation and review	Dorothy House and Healthwatch Wiltshire can illustrate the impact of including patient experience in the development of services				Aug 18

Meeting and engagement schedule including discussion themes

Date	Location	Venue	Time	Theme
Sept 4 th 2017	Dorothy House, Winsley		Am	Report to Clinical Governance Committee - Lucie Woodruff
Sept 8 th 2017	Peasedown St John Outreach Centre	Group Room	2 - 4pm	Year 1 report Jenny Steele, Communications Manager - a review of literature including leaflets, website, patients' pack, bereavement pack and the language included. Volunteers can take material away and complete in their own time. Agree communication material for promotion of the group through DH
Oct 6 th 2017	Dorothy House, Winsley	Meeting Room	10.30-12.30	Volunteers to feedback to Jenny Steele on communication review Training from DH on health conditions (30 mins)
Nov 17 th 2017	Trowbridge Outreach Centre	Large Meeting Rm	10.30-12.30	Ruth Gretton update on Patient Experience of Care Questionnaire project Phillipa Watson, Fundraising - a review of how the fundraising team communicates with the public in the light of changes to legislation Discuss engagement
Dec 2017	Dorothy House, Winsley		Am	Report to Clinical Governance Committee - Lise Griffiths
Nov/Dec 2017	No meeting - engagement			Engagement on the fundraising review with patients and carers (late November, early December). This will replace the December UAG meeting
Jan 26 th 2018	Dorothy House, Winsley	Meeting Room	10.30-12.30	Feedback on fundraising review engagement (1 hr) Steve Dale update (1 hr)
Feb 23 rd 2018	Trowbridge Outreach Centre	Large Meeting Rm	10.30-12.30	Update from Jenny Steele following communication review Karen Tudge Therapist Service - a review of physiotherapy, occupational therapy, complementary therapy and the dietician service to help shape the palliative reablement service Discuss engagement
March 2018	Dorothy House, Winsley		Am	Report to Clinical Governance Committee - Lise Griffiths
Feb/March 2018	No meeting - engagement			Engagement on the therapist service (late February, early March). This will replace the March UAG meeting
April 20 th 2018	Dorothy House, Winsley	Meeting Room	10.30-12.30	Feedback on therapies review and engagement (1 hr) Update from Philippa Watson following fundraising review
May 25 th 2018	Trowbridge Outreach Centre	Large Meeting Rm	10.30-12.30	Dave Smith Chaplaincy Service - a review of the chaplaincy service including literature, service plan, inpatient service, bereavement service and funeral services.

Date	Location	Venue	Time	Theme
June 2018	Dorothy House, Winsley		Am	Report to Clinical Governance Committee - Lise Griffiths
June 22nd 2018	Peasedown St John Outreach Centre	Large Meeting Rm	- 4pm	Volunteers to feedback on Chaplaincy service Update from Karen Tudge following therapies review
July 20 th 2018	Dorothy House, Winsley	Meeting Room	10.30- 12.30	Reflection and evaluation - Year 2 Update from Dave Smith following review of Chaplaincy service review
Aug 24 th 2018	Trowbridge Outreach Centre	Large Meeting Rm	10.30- 12.30	Review and report on year 2 Forward planning

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