

End of Life Day Therapies Review

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1.0 Introduction

In February 2013, Agewell was commissioned by Sandwell and West Birmingham CCG to undertake a patient and public survey about end of life day care. The aim was to find out from current and future users of the service what factors are important to them, so that this can inform commissioning of future services.

2.0 Methodology

A questionnaire survey form was developed with the CCG Commissioning Manager and members of a review group (see Appendix).

This questionnaire was taken to two groups of patients who attend Bradbury Day Hospice in Oldbury and to one group each of patients who attend day services at Mary Stevens Hospice in Stourbridge, John Taylor Hospice in Erdington, North Birmingham and at Compton Hospice, Wolverhampton. Questionnaires were also completed at these services by family carers and by volunteers.

St Marys Hospice, Birmingham distributed the questionnaires to one group of day patients, and eight questionnaires were completed there. In total 59 people completed questionnaires at these 5 venues.

To obtain the views of people who don't yet need end of life day care about their own aspirations and of people who may be family carers, the questionnaire was also taken to members of Agewell's local over 50s forums in the six towns of Oldbury, Rowley Regis, Smethwick, Tipton, Wednesbury and West Bromwich and to members of a knitting group. 90 questionnaires were completed at these forums.

Overall, 149 questionnaire forms were completed. In addition, informal feedback was supplied by two groups of patients who did not wish to complete a detailed questionnaire.

Interviewers also talked to senior staff on duty at the day services in order to obtain background information on the number of day patients they cared for and what services and activities were currently on offer.

3.0 Respondent Profile

Of the 149 respondents:-

- 73 were female, 18 male and 58 not disclosed.
- 19 were aged 80+, 57 were 66-79, 15 were 56-65, 10 were 40-55 and 48 not disclosed.
- 85 were retired, 11 employed full time, 3 volunteers or other and 50 undisclosed occupational status.
- 89 were English/Welsh or Scottish, 4 Caribbean, 2 African, 1 Irish and 1 Pakistani. 52 did not state ethnic origin.

4.0 Locations and Services Visited

4.1 Mary Stevens Hospice in Stourbridge

A charity funded Palliative Care Service, which supports patients through an inpatient unit with 10 bedroom spaces, day therapies service and home care from a combined hub of buildings in attractive grounds. Health care professionals can refer any patient with any life threatening illness for specialised palliative care with symptom control, respite and end of life care.

The Day Therapies Department runs Monday to Friday and can accommodate up to 18 patients per day, but this varies with dependence levels. On the morning of Agewell's visit 12 patients were present.

There is access on site to specialist treatment from a nurse led multidisciplinary team comprising nurses, physiotherapists, social worker, complementary therapists and doctors. The team has close relationships with other community services, such as occupational therapists, Macmillan and other specialist nurses. Patients can currently access 2 weeks respite care per year.

Staff commented that with advances in cancer care people with a terminal prognosis are surviving longer than the 12 month period designated as end of life care. There are very few support services for patients with terminal illnesses who experience a long prognosis period.

Day service patients come to the hospice through lifts provided by family or friends, or through the hospice's volunteer car scheme, or for the most severely ill, through Ambuline, a private ambulance service contracted to provide patient transport by Dudley CCG.

The day services area has an open plan lounge/dining room with a conservatory where there are table games and Wii and a garden and sitting out area. There are two separate therapy rooms. The open plan setting does place some limits on what activities can be provided, though many patients simply appreciate the chance to relax and chill out.

4.2 John Taylor Hospice in Erdington, North Birmingham

John Taylor Hospice offers residential care, day care and home care. Previously within the NHS, it became an independent social enterprise in 2011 and retains the support of a charitable League of Friends. Day services have places for up to 13 patients and run 4 days per week. On the morning of Agewell's visit there were 8 day patients, half of whom had advanced degenerative neurological conditions.

Patients come to the hospice through lifts from family or friends, through a volunteer car scheme or in the hospice's own adapted Peugeot vehicle which can take wheelchairs. The hospice is planning to buy its own minibus.

Day services operate in a spacious airy room with a separate dining area. A large flat screen TV has recently been installed, so that with a subscription to Netflix patients can watch films. The hospice has had funding for an artist in residence who has also supported patients who want to do arts and crafts. 4 patients were so engrossed in painting that they preferred to give informal feedback while continuing painting rather than taking time out to do a survey questionnaire. Day services have a separate therapy room used by someone who is training in complementary therapies. A social worker runs a clinic for day patients in the afternoon. Day patients have access to specialist pain relief and to a programme for managing fatigue, anxiety and breathlessness.

4.3 Compton Hospice in Wolverhampton

Compton Hospice offers a comprehensive range of inpatient, day and home care. Day services and home care operate from the Woods Day Therapy Centre, a building on the Compton site within attractive woodland.

Day services can cater for up to 16 people and runs 5 days per week, though average attendance is 9 per day. On the morning of Agewell's visit there were 8 patients.

Patients come to the day centre through lifts from family and friends, through a volunteer car scheme or through the hospice's 2 adapted vehicles which can carry up to 5 people. The hospice has its own ambulance vehicle, though this is used less often. Staff described the volunteer car drivers as an important link between hospice and home. Volunteer drivers often made friends with the patients they were transporting door to door, were able to see the patients at home and thus able to alert staff to any adverse change in circumstances.

Day services run in a combined lounge and conservatory with a separate dining area. There are extra rooms for therapy and counselling and several areas for sitting out in. A volunteer art tutor was working with patients on the morning of Agewell's visit, and 2 nail art/manicurist beauticians were coming round to each patient.

While there, Agewell staff observed a practical demonstration of sensitive bereavement support and of the power of peer support. The senior nurse on duty had to break the news to the patients that one of their number had recently died. The patients were very upset, but drew strength and support from each other, and one said: "Together, we are strong."

4.4 Bradbury Day Hospice in Oldbury

The Day Hospice operates on the ground floor of a detached house. Upstairs is a base for Community Specialist Palliative Care Clinical Nurse Specialists who organise urgent home care packages for hospital patients who wish to be discharged to die at home.

Originally a satellite service managed by Compton Hospice, the Bradbury Centre is now run directly by Sandwell and West Birmingham Hospital Trust, though is not listed on the SWBHT website.

The day hospice centre can cater for up to 14 patients on 4 days per week, though attendance is usually up to 12 per day. Agewell staff and volunteers visited on 2 consecutive mornings, when 7 patients were present each time. Some patients are able to attend the day hospice twice a week.

Most patients come to the day hospice through lifts from family or friends. A Passenger Transport vehicle is on loan, and the hospice has one handyman/driver, but this service is limited, and transport routes and journey times are long and off putting, especially for residents in distant parts of Sandwell borough, such as Great Barr. Bridges Cancer Support, which recruits volunteers to work in the day hospice, has had to end a volunteer car service.

Within a combined open plan lounge and dining area opportunities for various informal activities are on offer. 3 patients who were engrossed in a jigsaw preferred to give informal feedback rather than complete a survey questionnaire. Complementary therapies are not currently on offer, but there is a gentle exercise programme. Nurses undertake regular observation of each patient and make referrals as necessary to physiotherapists, occupational therapists and social workers within the hospital Trust, as these are not available on site.

5.0 Survey Findings

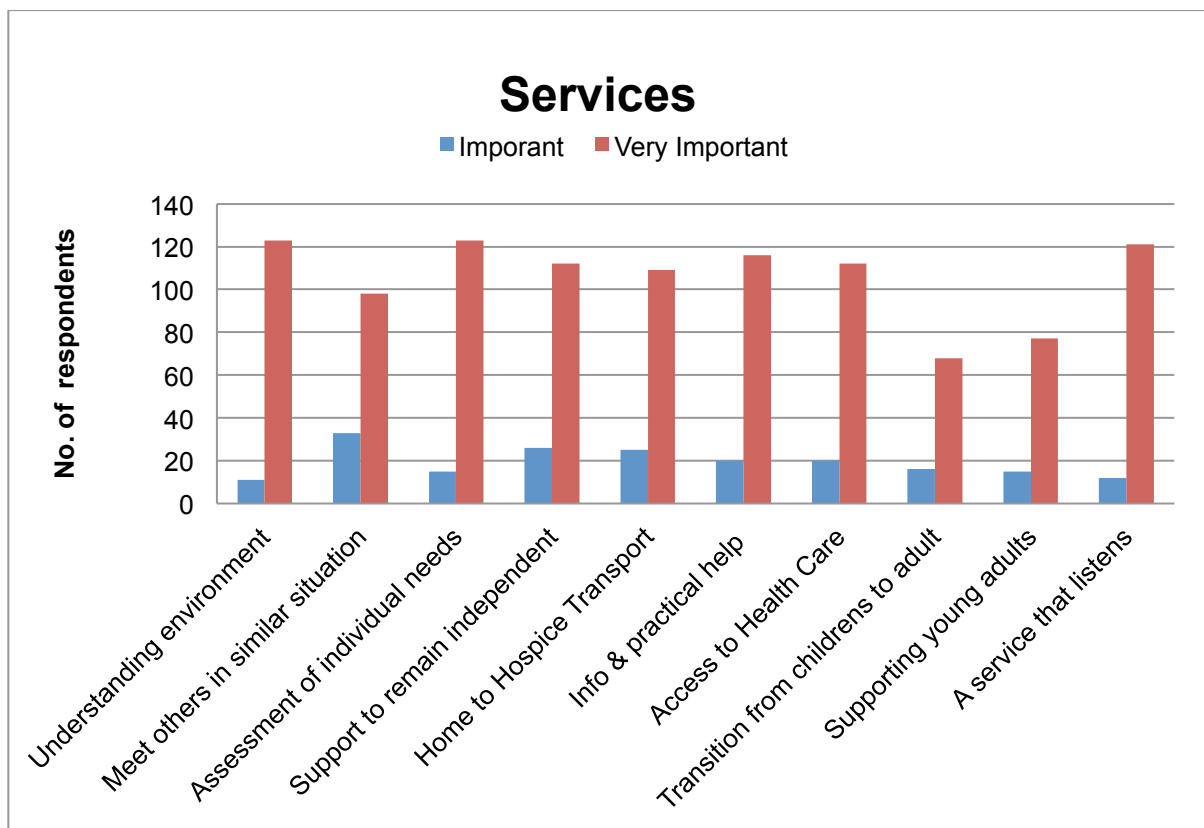
Question 1

Respondents were asked what they thought was important for a Day Hospice or Day Therapies to provide. Responses were not ranked, i.e. respondents ticked everything they thought was important.

The results show there was a high degree of consensus among respondents:

- 138 people rated on-going assessment of needs as important or very important.
- 138 people rated support to remain independent as important or very important
- 136 people rated the supply of information and practical help as important or very important.
- 134 people rated the opportunity to relax in a clean, safe and understanding environment as important or very important.
- 134 people rated the provision of home to hospice transport as important or very important.
- 133 people described a service which listens as important or very important.
- 132 people described access to health care professionals as important or very important.
- 131 people described peer support, the opportunity to meet others in a similar situation as important or very important.

'Other' factors mentioned were support and love from staff and visiting volunteers; understanding, friendly people and service; emotional support and respite for carers.



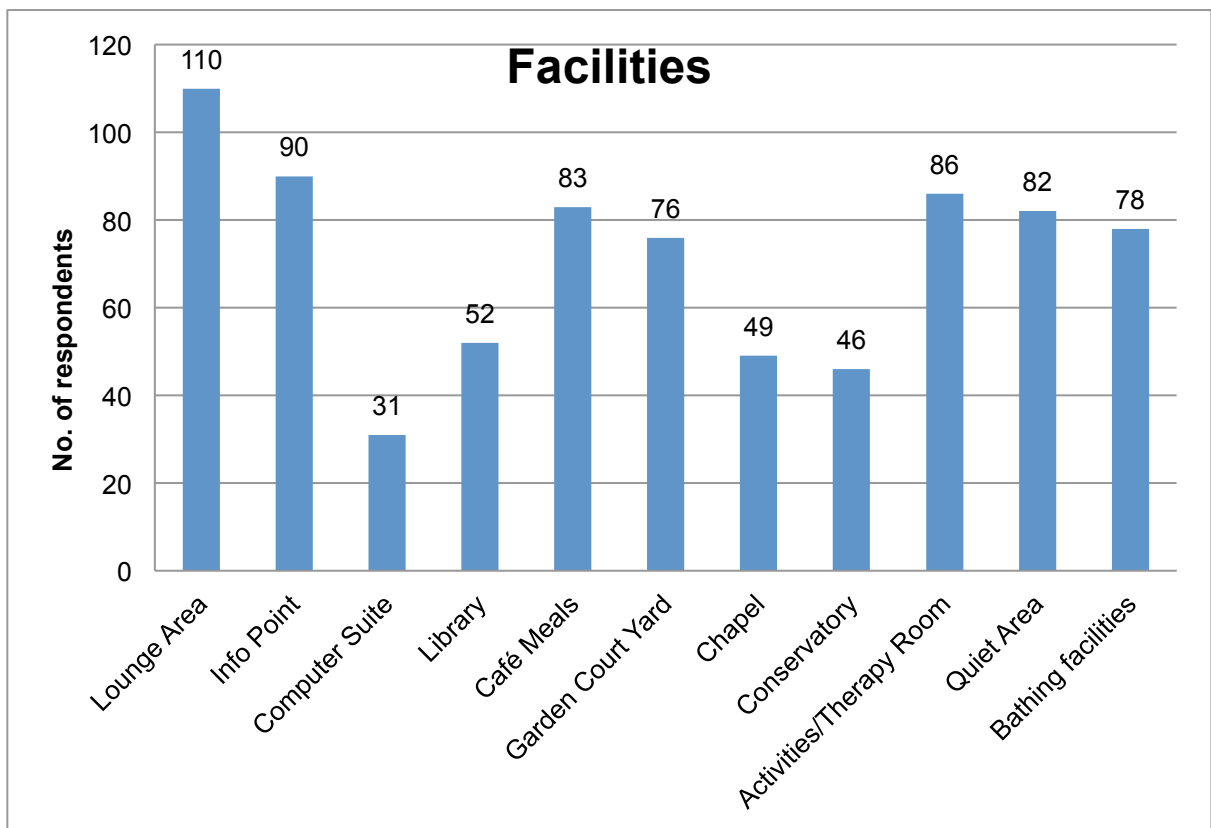
Question 2

Respondents were asked what facilities were important for a Day Hospice or Day Therapies to provide.

Those who were patients tended to describe the facilities they already had, but there was consensus among all respondents about what was most important.

From the options on the questionnaire, those mentioned most frequently were: a lounge area, an information point, a room for activities or therapy, a café for provision of meals, a quiet area, adapted bathing facilities and a garden or courtyard to sit out in.

Responses to 'other' included occupational therapy, a separate dining area and services to help people who are visually impaired.



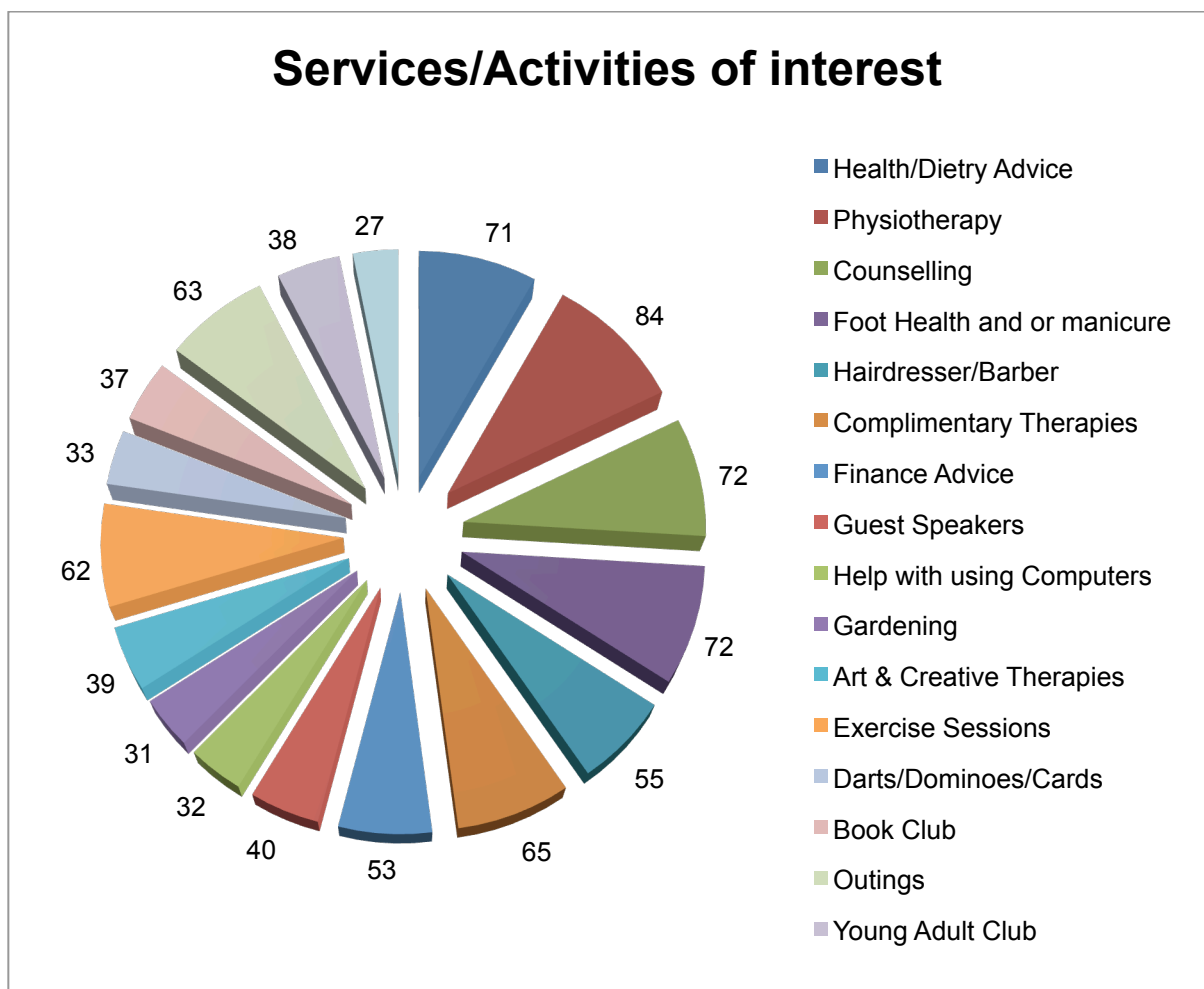
Question 3

Respondents were asked to pick from a list which services or activities they would be most interested in. The results indicate they would like a wide variety and choice. Patients tended to mention services or activities they already had which they valued.

The 10 most popular services or activities ticked were:

1. Physiotherapy	84
2. Counselling	72
3. Pedicure/manicure	72
4. Health and dietary advice	71
5. Complementary therapies	65
6. Outings	63
7. Gentle exercise sessions	62
8. Hairdresser/barber	55
9. Financial advice	53
10. Guest speakers	40

'Other' services mentioned by respondents included Bingo, a reading or audio book group, a garden, an art gallery, Tai Chi, a mini cinema, a gym, a hospice shop and signposting to other services.



Question 4

Respondents were asked what time they would like to attend the Day Hospice or Day Therapies, and when the service should be available.

Answers to this question were inconclusive. Existing patients indicated they were grateful for the one day per week or two days per week they were able to attend.

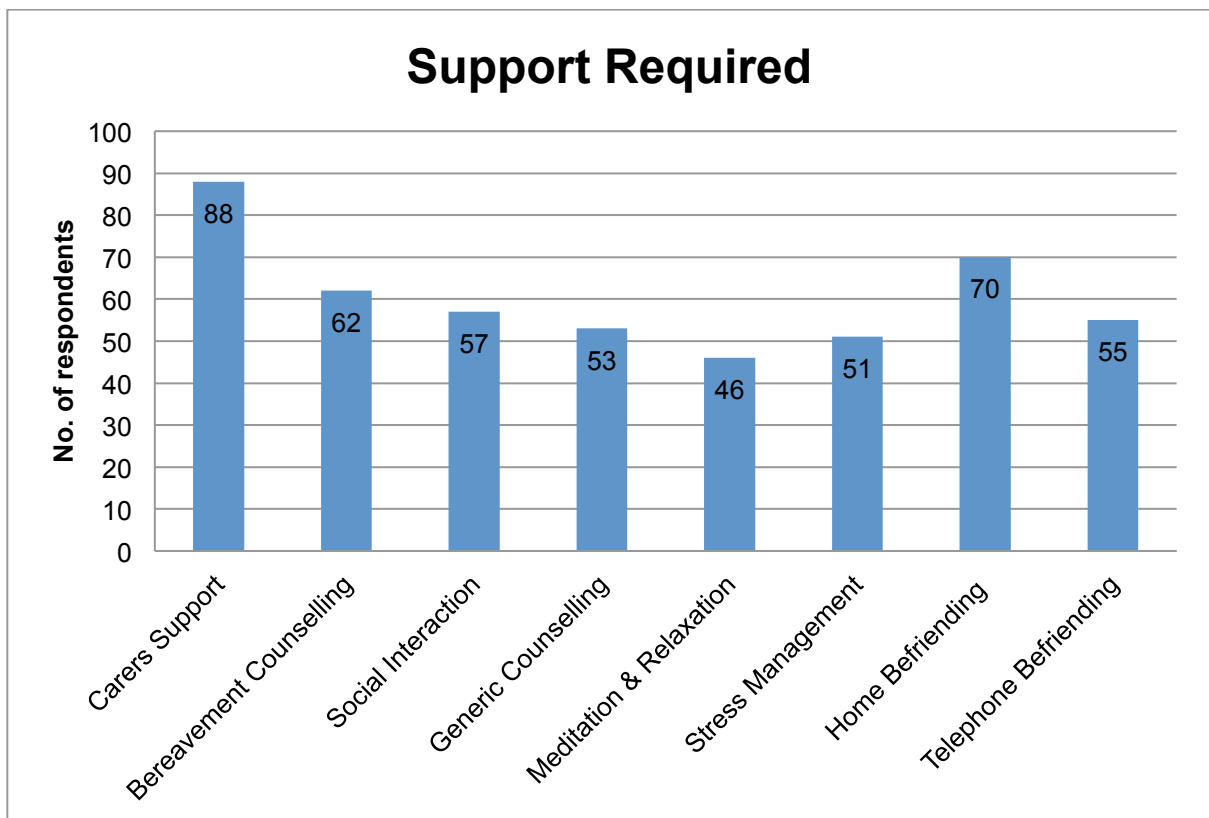
Other respondents had a more idealised view that Day Services should be open 5 or 7 days per week and that people ought to be able to attend according to their individual needs.

Question 5

Respondents were asked what support was required (at home) outside of the Day Hospice/Day Therapies setting.

88 people responded to this question. From the options on the questionnaire, respondents selected support for carers as the most important. This was followed by a befriending home visiting service, bereavement counselling, social interaction, a telephone befriending service, generic counselling, stress management and meditation & relaxation.

In response to 'other', patients described services they already received which they considered a lifeline and specifically mentioned quality home care services, specialist equipment and adaptations, gardening and mobile hairdresser.



Question 6

Respondents were asked what activities and/or services they felt could be provided in their local community.

45 people responded to this open question. Answers included what people knew was already available, but would like to see more of, and included:

- Support groups for younger hospice patients
- Home visits
- Financial information
- Adaptations for independence
- Support from District Nurses
- Extended night sitting services
- Transport for users of electric wheelchairs
- More day centres
- Meetings and social events
- Arts and crafts, knitting, film making/drama group
- Games clubs, swimming, table tennis, snooker, fishing
- Reminiscing groups and activities for people who have dementia
- Volunteer scheme from a local college

Question 7

A number of respondents, mainly patients or carers, took the opportunity to offer open feedback when asked if they had any other comments. Here's what they had to say:

"Getting out of the house is most important. I have learnt things from other patients. Staff are brilliant, and we can talk about anything."

"Coming here means getting a day out. Help with my medication is very useful."

"Coming here means I don't have to stay at home looking at 4 walls and is something I look forward to."

"I'm very happy with all the services provided here."

"I don't always want organised activities – it depends how well I feel. Getting out of the house once a week is important. I see this place as somewhere to come, rather than going on outings."

"Without this service I'd be very lonely."

"Volunteers make all the difference."

"I pads for service users would be good. GPs only treat the medical condition, so having some singers and beauty therapists coming into the centre on some days would be nice."

"Services need to have access for assistance dogs."

"A chaplain and physiotherapy would be nice."

"Not enough help is given to service users who have dementia."

“Coming to day care should not be stressful. The patient and their carer need time to have breakfast and get ready, bearing in mind the difficulties this may entail. There should be sufficient time at the centre to enjoy it, but not get over tired. Allow time to travel there and back. Time to get home, and for the patient and their carer to carry out late afternoon and evening tasks like bathing, medication and preparing meals.”

“I don’t want to feel pressure from health or dietary advice.”

“It is important to use all the skills of local people in the area too – they are a great resource! More services should be locally based, using all community bases with a wider variety of themes.”

“How necessary is this survey? Everything listed should be available to all, to support patients with dignity and respect, which does not happen in care homes. It is time to get it right.”

Two groups of patients who preferred not to interrupt their existing activities offered the following feedback:

“What is important about coming here is company, friendship with other patients and getting out of the house.”

“I look forward to coming here; before, I was ready to go round the bend.”

“It eases my conscience with what’s wrong with me.”

“Staying independent and in your own home is very important.”

“We rely on relatives for transport everywhere, but don’t want to over burden them.”

“We’d be willing to pay for meals here if that helps the finances.”

“Having a regular health check from nurses on duty here is good.”

“Other activities we have enjoyed here – knitting and making cards and gift bags.”

“Caring staff and volunteers are very important.”

“Company of other patients and support for each other is important.”

“Choice of a wide range of activities is important.”

“Transport is crucial; without it we are trapped and isolated.”

“Support to remain independent is very important. A key part of this is competent home care and support from staff willing to take direction from the service user.”

“Access to a social worker for practical help is very important.”

“Doing art and having the support of an artist in residence is very enjoyable.”

“Having a massage here is very helpful.”

6.0 Emerging Themes

There was wide consensus among respondents about the importance of holistic day services, offering choice from a wide range of activities and services, and the key nature of supportive relationships formed with staff, volunteers and other patients.

Volunteers were an integral part of most day services, extending activities on offer, providing a listening ear and a link with patients at home.

Patients who went to day services provided from a hub where home care and inpatient services were also based, benefitted from a wider range of services and quicker access to specialist support.

Patients talked about the importance of coming out to day services, getting a change of scenery, and some indicated that before they came to day services their mental health had been poor.

Transport was viewed as a vital part of day services, because people in poor health are unable to use public transport, and taxi fares are prohibitively high. Transport was the major barrier to using any other services elsewhere, so the day services became patients' sole lifeline.

Support to remain independent was highly valued, with patients describing domiciliary services. Emotional support, whether counselling, bereavement support, befriending, carers' support or help/techniques to manage stress were widely listed as important among all survey respondents.

Ideas about services in the community indicated the importance attached to combatting the social isolation which illness and disability can cause.

Staff and some patients raised an issue which needs consideration by commissioners and patient participation groups currently working on a strategy for care and treatment of long term conditions. Advances in cancer care mean patients with a terminal diagnosis are surviving longer, and patients with degenerative neurological conditions continue to require palliative care for a longer period than the 12 months formally described by NIHCE as end of life.

7.0 Acknowledgements

Agewell would like to thank everyone who responded to the questionnaire, but in particular the patients, family carers, staff and volunteers at the day services who so graciously gave us their time.

8.0 Appendix



Day Therapies Review

Agewell have been asked by Sandwell & West Birmingham CCG to meet with you today to gain your opinions of the services you would like to see provided as part of **Gold Standard Day Hospice** provision. When giving your answers you might like to consider services/activities you feel could also be made available in your local community.

Venue:

Are you: A Patient A Carer A Family Member Staff Other

1. What do you think is important for a Day Hospice/Therapies to provide? (Please rate 1 being least important and 5 being most important)

Peace, quiet and the opportunity to relax in a clean, safe, supportive and understanding environment.	① ② ③ ④ ⑤
An opportunity to meet others in a similar situation.	① ② ③ ④ ⑤
On-going assessment of individual needs.	① ② ③ ④ ⑤
Support to remain independent.	① ② ③ ④ ⑤
Home to Hospice Transport.	① ② ③ ④ ⑤
Information & practical help for patients and families.	① ② ③ ④ ⑤
Access to Health Care professionals.	① ② ③ ④ ⑤
A successful transition from children's to adult services.	① ② ③ ④ ⑤
Supporting young adults with independence, life choices, access to work and education opportunities.	① ② ③ ④ ⑤
A service that listens.	① ② ③ ④ ⑤
Other	① ② ③ ④ ⑤

2. What sort of facilities should a Day Hospice/Therapies have? (Please rate 1 being least important and 5 being most important)

Lounge Area	①	②	③	④	⑤
Information Point	①	②	③	④	⑤
Computer Suite	①	②	③	④	⑤
Library	①	②	③	④	⑤
Café /Meals	①	②	③	④	⑤
Garden/Courtyard	①	②	③	④	⑤
Chapel	①	②	③	④	⑤
Conservatory	①	②	③	④	⑤
Activities/Therapy Room	①	②	③	④	⑤
Quiet Area	①	②	③	④	⑤
Bathing Facilities	①	②	③	④	⑤
Other:	①	②	③	④	⑤

3. What services / activities would you be interested in? (1 being least interested and 5 being most interested in)

Health/Dietary Advice	①	②	③	④	⑤
Physiotherapy	①	②	③	④	⑤
Counselling	①	②	③	④	⑤
Foot Health and/or Manicure	①	②	③	④	⑤
Hairdresser/Barber	①	②	③	④	⑤
Complimentary Therapies Massage/reflexology/Reiki/Aromatherapy	①	②	③	④	⑤
Financial Advice	①	②	③	④	⑤
Guest Speakers	①	②	③	④	⑤
Help with using computers (e.g. internet, email)	①	②	③	④	⑤
Gardening	①	②	③	④	⑤
Art & Creative Therapies (pottery, silk and glass painting)	①	②	③	④	⑤

Exercise Sessions	①	②	③	④	⑤
Darts/Dominoes/Cards	①	②	③	④	⑤
Book Club	①	②	③	④	⑤
Outings, planned to meet everyone's needs	①	②	③	④	⑤
Young Adult Groups	①	②	③	④	⑤
Meditation e.g. Yoga	①	②	③	④	⑤
Other:					
	①	②	③	④	⑤

4. What is the most suitable day and time:

What time would you like attend the Day Care Hospice?
How many days a week should the Day Care Hospice be available?

5. What support would you need outside of the Day Hospice/ Therapies setting?

Carers Support (Respite)	①	②	③	④	⑤
Bereavement Counselling	①	②	③	④	⑤
Social Interaction	①	②	③	④	⑤
Counselling	①	②	③	④	⑤
Meditation & Relaxation	①	②	③	④	⑤
Stress Management	①	②	③	④	⑤
Befriending Service (home visits)	①	②	③	④	⑤
Befriending Service (telephone)	①	②	③	④	⑤
Other:					
	①	②	③	④	⑤

6. What activities and/or services do you think could be provided in your local community?

	①	②	③	④	⑤
	①	②	③	④	⑤
	①	②	③	④	⑤
	①	②	③	④	⑤
	①	②	③	④	⑤
	①	②	③	④	⑤
	①	②	③	④	⑤
	①	②	③	④	⑤

7. Other Comments/Ideas

Thank you for your time and comments we will keep you informed of the outcome.