

## Living with and Beyond Cancer Focus Group

Living with and beyond cancer is a national programme looking to improve the breadth of services for patients and families who have cancer. On December 10<sup>th</sup> 2018 the Living with and beyond cancer team of Wye Valley Trust and Macmillan jointly hosted a focus group in Hereford with Healthwatch, for people who have or have had cancer and family and friends to share their experiences and views on cancer care. The aim of this feedback is to shape the plans for the local living with and beyond cancer programme over the next two years.

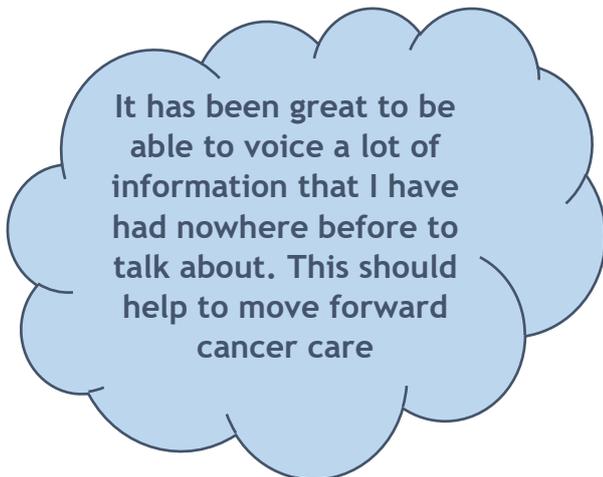
### Comments ....

Very informative. Lots still to be done.

Overdue but fantastic it has come together.

Very interesting to hear other people's thoughts and views. Great to hear cross border discussions. Really worthwhile coming thank you.

Good stuff, well organised.



A useful start, keep going.

Very interesting & informative. We couldn't have done more with the time and group size. Let's see the output and focus.

Interesting, thought provoking and informative. Well facilitated by the facilitators, who were extremely helpful and knowledgeable.

About time.

Perhaps an invitation to family members or spouse is a good idea, since a lot of cancer patients would not want to attend.

### Introduction

The attendees were divided into three smaller groups with a facilitator on every table. The group was asked to consider the question:

**'What should good cancer support look like for patients and their families?'**

After collating all of the suggestions the facilitators grouped the comments into the common themes of:

- Information
- Communication
- Support services
- Psychological/emotional
- Transport
- Specific services
- Systems
- Caring and carers
- Other

The public were then asked to vote for 3 preferred ideas from all of the comments

Those that were chosen are below with the number of votes:

**Aftercare support centre** - support groups, counselling, nutrition, and access to diagnostics specific to cancer history. **6**

**Integration** - Joining up of services beyond Discharge. **3**

**A named person or GP to go to** - for support information on medical or emotional issues. **3**

**Family Aftercare** - Partners, Close friends, Parents, Children. **2**

**Training of district nurses.** E.g. provision of treatment close to home or the night time. **2**

**Use of telemedicine** **2**

**Holistic needs assessment looking at the whole person** - helping to find way through what's on offer including psychological. **1**

**Better education of GP's on metastatic diagnosis or a Macmillan Renton Unit service for post treatment follow up which can be accessed ongoing.** **1**

**Discharge planning across borders.** **1**

**Cancer nurses at every GP surgery.** **1**

**Confidence in unpaid family carers** - Training course for carers. **1**

**Access to cancer specific professionals** - to avoid GP's. **1**

**Buddy scheme.** **1**

**Time** - an afternoon became a day, why? What's the blockage? Has impact on family and leads to low tolerance. **1**

**Reduce time spent on the cancer unit when you don't have much time left to live.** Need better systems. **1**

**Reduce isolation.** Some people have no family and friends network to help them through cancer. **1**

**Social prescribing** - extension to community. **1**

**Good signposting for next steps** - and additional communication for family members. **1**

The following are all of the suggestions grouped into themes

### Information

- Didn't know about free sessions Yeleni centre, found out from the Macmillan bus in town.
- Cancer specific information boards in Macmillan Renton Unit.
- Move the Macmillan support centre to the foyer.
- An NHS 111 style cancer specific helpline.
- Clinical checklist to include referring all people to the Macmillan information & advice service, not everyone gets to this service.
- Too much paper, need electronic systems instead of folders of paper.
- Help with home finances and home issues e.g. Telecare, safety checks, handyman, motion sensors etc.
- WISH isn't working well enough, need to know what questions to ask or search for to find the right physical wellbeing information. Looking for things to motivate me to get better. Sign posters need to be well informed.

- Improve signposting to information write info on local diagnosis to be given personally to patient.
- The negative effects of the internet. Advice to navigate good and bad advice, Help is in blue information folder on how to do this.
- Decision for patients to make about treatments options is difficult. Provide ways to help explore this and make a decision. This has a big impact on family too.
- Blue information folder. Too much information at the time and need support to use the folder, lots of things happening at this point, it is very scary.
- Social prescribing, people don't always know what to ask for.
- Blue information folder. Maximise it, sometimes it is frightening to think about looking at it.
- Develop a database for external factors associated with cancer nationwide.
- Go to contact in Powys.

## Communication

- Use TV's in units to promote all local cancer support services.
- Need Wi-Fi access to all patients in the Macmillan Renton unit.
- Understanding and navigating services, e.g. Out of Hours, Taurus Hereford medical group, Taurus etc.
- Explanation of results in primary care.
- Advance care planning.
- Regular feedback sessions for patients.
- Reduce Jargon.
- Care plan to include carers.



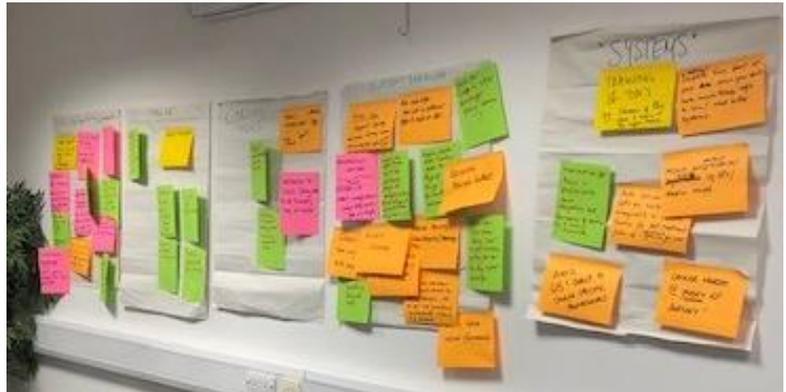
## Support services

- Paid for live in 48 hour discharge sitting service.
- Remote region support (rural areas).
- People who don't have family told to get someone to stay for a few days after discharge. Not everyone has a network.
- Cancer specific gym, advice, training.
- Finding people with similar interests to do physical group things. Walking for health, exercise, yoga etc.
- Herefordshire carers support provide tips to help with advance planning and contingency planning of practical arrangements for the cared for person while I have cancer.
- Medical knowledge, more information regarding different type of medicines on offer.
- After care support centre - support groups, counselling, nutrition, access to diagnostics specific to cancer history.
- Mindfulness sessions, yoga, exercise very important. Group stuff gives you a target.
- Support group from last review with oncology.
- Access to nutritional therapists for helping manage side effects.

- We are all individuals, treatment should be person specific - not as per NHS guidelines as no flexibility, listen to the patient.
- Holistic space indoors which is not medical.
- Buddy scheme.
- Support groups mindfulness to deal with anxiety and normalise living with cancer.
- Good signposting for next steps and additional communication for family members.
- Social prescribing extension to community.
- Powys community connectors.

## Psychological/emotional

- Physical changes due to treatment, body image issues and psychological impact need support.
- Psychological support for cancer patients
- Need named person or GP to contact with number for support/ information on medical emotional issues.
- Need spirituality fulfilled. What goes on for specific for cancer patients?
- Talking 1-2-1 with psychologist about anxieties, uncertainties, finances etc.
- What does stay positive actually mean? Need practical advice and steps.
- Fear of cancer returning, dealing with uncertainty.
- Relationships, particularly with partners, how you face problems together. Psychosexual support, need support for this.
- Physical effects on family relationships has a huge impact. Bereavement services
- Psychological effects on family especially when cancer are terminal, and the affect after death on family.
- Holistic needs assessment, finding your way through what's on offer for psychological support.
- Isolation - So many of us now live alone with limited living family members, how can we improve community connections.
- My diagnosis led to some challenging emotional consequences and I did not feel I had an avenue of reassurance. I wanted be able to pick up the phone to a service that was not over-busy and to feel reassured about my fear of what the diagnosis meant for the long term. I did not feel well supported overall and would have benefited from seeing a cancer specialist counsellor much sooner.



## Transport

- Transport out of county for treatment. Who can help? What are patient rights? Who can or will pay?
- Patient transport.
- Length of waits for return transport when accessing treatment has a big impact.

## Specialist services

- Adolescent cancer arrangements are complicated, university vs home.
- Responsive social care after discharge.
- Understanding nutritional needs.
- Comorbidities. Consultants and pharmacies review interoperability of drugs and the long term effects of treatment.
- Infertility considerations before treatment.

## Systems

- Training of district nursing e.g. provision of treatment close to home or at night time.
- Improve/reduce time spent at cancer unit when you don't have much time left to live. Need better systems.
- Discharge planning across county borders to speed up process.
- Information for public and professionals about integration and the boundaries of service e.g. District nursing and homecare.
- Access to all patient medical records by GP's and hospice staff. (Shared records).
- Better education for GP's on metastatic diagnosis or Macmillan Renton unit service for post treatment follow up ongoing.
- Cancer nurses at every GP surgery.
- Use of Telemedicine particularly for follow up appointments.
- Avoid GP's by accessing cancer specific professionals.
- Joining up of services beyond discharge.
- GP's access imaging from consultants.



## Caring and carers

- Confidence to carers, they are capable (they need to be trained).
- Family aftercare - partners, children, parents, close friends.
- Managing my caring responsibilities when I have cancer and appointments.
- Training courses for carers, give confidence to unpaid family carers.
- Empowering carers by including them in care planning. Use triangle of care model.

## Other

- Employers understanding of employees with cancer.
- Flexible working.
- Time - and afternoon became and day, why? What's the blockage? E.g. pharmacy. Impacts on family life which leads to lower tolerance.
- Knowledge in advance regarding finances and work, returning to work on a phased return.

## Follow on

The feedback in this report will be used by the living with and beyond cancer team in their two year work programme. It will also be shared with the participants who consented to keep in touch with the programme. It is our intention to run a similar day time event in the spring of 2019.

### Appendix:

#### Breakdown of focus group

5 facilitators

11 Attendees

10 feedback forms completed

Female 6

Male 4

People who are family member or friend of someone with cancer 3

Number of people who have had a cancer diagnosis for:

6 months - 2 years 1

2-5 years 3

5 years or more 3

#### Age

36-45 1

46-55 4

56-65 3

66-75 2