

Living with and Beyond Cancer Focus Group

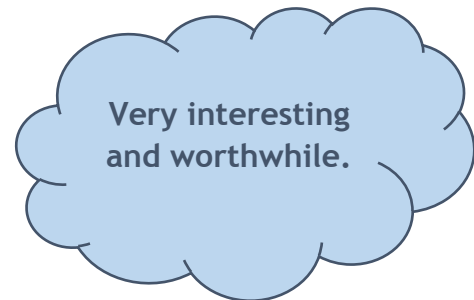
Living with and beyond cancer is a national programme looking to improve the breadth of services for patients and families who have cancer. On April 25th, 2019 the Living with and beyond cancer team of Wye Valley Trust and Macmillan jointly hosted a second focus group in Hereford with Healthwatch, for 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

Excellent!

Thought Provoking

Excellent
brainstorming



Introduction

The attendees were divided into two small 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
- Mental Health
- Transport
- GP's
- Diagnostics
- Carers and families
- Allied Health professionals

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:

- Fear of recurrence. **3**
- Support to continue working. **2**
- Listening and psychological skills training for patients/carers to help support one another. Peer support. **2**
- Post treatment side effects support **2**
- Community and support for carers and patients. **1**
- Key point of contact. Cancer Nurse Specialist (CNS) key person. **1**
- One record for a patient which includes everything. **1**
- Isolation due to lack of transport. **1**
- Access to the same GP. **1**
- GP doesn't know information to signpost. Would like information on signposting. **1**

- GP's not knowing what services are available, e.g. lymphoedema. 1
- Peer support 1
- Diagnostic pub - meet in public house to discuss issues 1
- Men screening. E.g. proper MOT whilst under care for anything. Making every contact count as men do not readily seek out medical advice¹
- Early prevention & detection. 1
- Late effects clinic. 1
- Expansion and coordination needed for increasing community voluntary transport. 1

The following are all of the suggestions grouped into themes

Carer and family

- Sex effects on relationship.
- Supporting adult children.
- Stages of grief can be later effects.
- Planning practically and emotionally for death.
- More support services longer term for the spouse.
- No bereavement support for the spouse.
- Family survivors.
- Care for animals when undergoing treatment and feel unwell.
- Support for the family survivors.
- Church support can be time limited.
- Working carers struggle with transport as they are often the taxi driver.
- Peer support to help mental health.
- Carers need support to be able to support.
- Becoming a formal carer is not always possible as there are eligibility criteria and cancer can be up and down and time limited.
- The toll of support can have a ripple effect into other areas.
- Often support isn't long term.
- It is like a roller coaster and support is needed off and on.

Information & communication

- Improved communication between hospital services.
- Information breakdown.
- Trusted information
- Busting myths.
- Key point of contact. Cancer Nurse Specialist (CNS) key person. 1
- One record for a patient which includes everything. 1
- Information - having it before, during and after treatment. Also being to talk about it many years later and impact it has had on all aspects of life.
- Being given a repeat opportunity to hear important information again.
- When care comes to a close, give information about living with and beyond cancer.
- National awareness needed about dietary needs, small portions and liquid diets.

- Preparing for side effects and when.

Support

- Reasonable adjustments for patient carer at work.
- Support groups with cancer peers.
- More carers support specific groups.
- Support 6 years on.
- After support for yourself.
- Law information about supporting someone who is working throughout family cancer.
- Support to continue working. 2
- Post treatment side effects support 2
- Hope support service for children.
- Group support long term.
- Support at whatever stage.
- Not enough time to plan finances towards death.
- Community and support for carers and patients. 1
- Previous patients as advocates to help others.
- Online forums for specific cancer, not generic.
- It is a unique experience for each person.
- Giving back through peer support advocates.
- Sempai (the senior student) experts by experience to buddy and help others.

Mental Health

- Mental wellbeing.
- Finding Acceptance.
- Body image issues both physical and emotional.
- Counselling and listening services.
- Listening and psychological skills training for patients/carers to help support one another. Peer support. 1
- Fear of recurrence. 2
- The what ifs remain stuck in one's mind. Spiritual.
- Singing.
- Mindfulness.
- Training in communication skills, e.g. advances communication level 2 skills training for professionals.
- Someone to talk to about illness and relationships.

Transport

- Isolation due to lack of transport. 1
- Parking, cost and time needed can be long appointments all day.
- Improved public transport network needed.
- Financial implications for the costs of travel for treatment and appointments.
- Patient miles.
- Timing of community transport can mean very long days for patients.

- Transport to access support outside of the treatment needed too.
- Enduring transport when sick.
- Expansion and coordination needed for increasing community voluntary transport. 1

Diagnostics

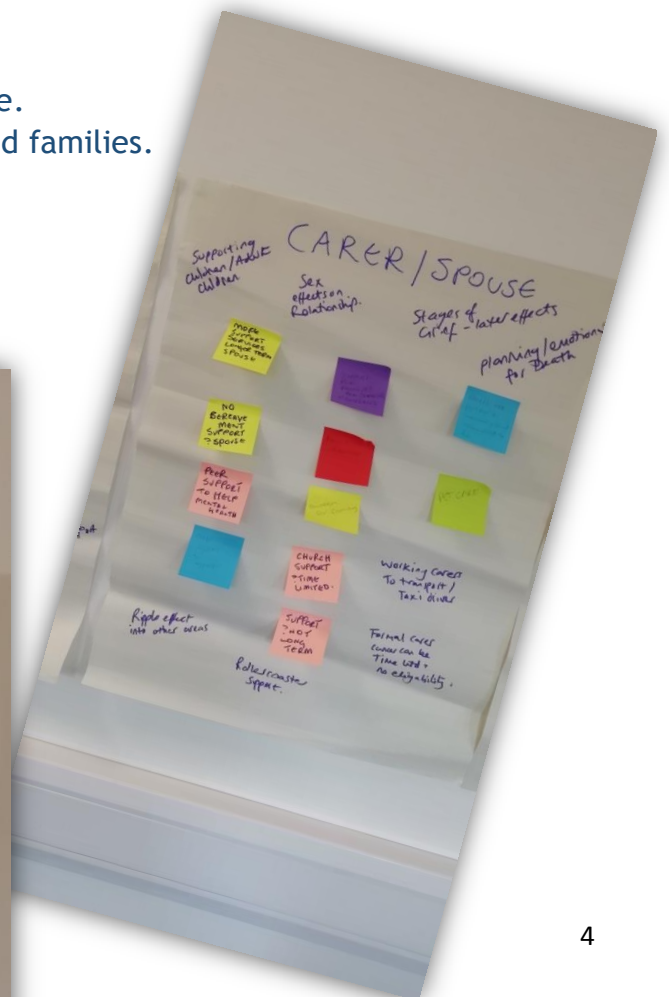
- Diagnostics
- Earlier tests, e.g. ovarian 3 yearly
- Diagnostic pub - meeting in the pub to discuss issues 1
- Men screening. E.g. proper MOT whilst under care for anything. 1
- Making every contact count
- Earlier prevention and detection
- Mobile screening services out to rural localities.

GP's

- Access to the same GP. 1
- Care out of hospital as much as possible.
- Someone specific to cancer in the GP practice.
- GP doesn't know information to signpost. Would like information on signposting. 1
- GP's not knowing what services are available, e.g. lymphoedema. 1
- GP Practise social prescriber/information officer.
- How to access the pathway for recurrence quickly and easily at the hospital.
- Making every contact count.

Allied Health Professionals

- Bathing services and help.
- Pharmacy support with medication and advice.
- Medicines compliance support for patients and families.
- Physiotherapy and Occupational therapy.
- Dietician.
- Late effects clinic. 1
- Carers and families.



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 feedback session in November 2019.

Appendix 1:

LIVING WITH AND BEYOND CANCER - 'MY EXPERIENCE'

In 2015 I was diagnosed with life threatening, grade 2 invasive ductal breast and lymph nodes cancer (18/29)

I was 53 years old

I was married

My daughter was in her first year at University

My son due to start his mock exams

My father in law was ill

We were going to decorate the lounge

I was on my way to work

I had no time for this

I had to survive ...

I'd had no lump or pain but mentioned to the new Practice Nurse at a routine Surgery appointment about a slight change that I thought was hardly worth mentioning.

Even when I was given a slip of paper to take to the MacMillan Renton Unit, I was not thinking it would be cancer.

After a prompt mammogram, ultrasound and biopsy, I was told to be back in a fortnight for surgery, to be followed by chemotherapy and radiotherapy.

I was stunned.

I cannot fault the speed and professionalism, I was dealt with, it ran like clockwork, which was just as well, I didn't have time to think but when I did, I thought it was a gift to know, if it hadn't been found, then I wouldn't be a survivor today.

I'm the sort that likes to know, to be informed, to take control of what I can, to have a plan, so I did.

I surprised myself with how calm I was, in the little pre-op room or should I say cupboard, I think partly because I had worked in the NHS, I didn't have white coat fever that most would and waited for the Anaesthetist.

I woke up on Teme Ward with the worst headache and retention ever but relieved all had gone well.

I left the ward with a drain in a shoulder bag, kindly donated by Hospice volunteers.

On discharge the Neighbourhood team visited daily to dress the drain site and give stem cell injections and Breast Care Nurses rang to check recovery.

Given time to recover, the next stage was Chemo, in my case 6 sessions in Hereford.

So I went to the hospital pre-chemo information session, where you are given a thermometer and told about what to expect, again I prepared what I could - like getting simple pain killers, a softer toothbrush, mouthwash, I stocked up with hand gel, wipes, creams, olive oil shampoo and colleagues had given me a couple of sick bowls and gloves.

I even colour coded the family towels.

I remember whilst being in the waiting area at MRU, catching sight of a young woman with short hair re-growth, saying ... it's not so bad, live in the moment ... and I thought, yes, I'll try to be like her, she'll never know how inspirational she was.

Every waiting area amazed me, with the number of people having treatment and even if on your own, there was always someone to talk to, if you wanted and friendly volunteers with tea.

After the first session I came away with a bag of meds and a sharps box, as soon as I got home, I would write out what to take and when.

The first few days after each session were the worst, then just when you start feeling better, it's time to go again.

Had a day out with friends to Embrace cancer shop in Worcester to buy hats and scarves to cope with the impending hair loss, although I did later attend Peruke for a NHS wig through a hospital referral but managed with the hats and was more concerned over my lashes and brows, which fortunately didn't disappear at the same time.

The next stage of the journey was literally a journey to Cheltenham for Radiotherapy, again given a file of information on how to prepare.

Volunteer drivers help to get you there, picking up others on route, so you could be out all day, making friends for life.

In my case, 15 daily sessions, not including weekends, which started with being positioned, measured and marked up with a tattoo pen. Towards the end, when I was getting travel sick, I was fortunately transferred back to Hereford

As soon as my hair started growing again, I had my ears re-pierced, to have some 'bling' around my face.

I wear a sleeve to this day and have regular check-ups with the Lymphoedema nurses.

I've had strangers say, oh what have you done to your arm? not expecting me to say ... it's a side effect of surviving cancer.

Around the time of treatment, a song by Kelly Clarkson, Invincible, was in my head and summed up how I felt.

A colleague and friend had lent me *The Secret* and other *Mindful* books before my diagnosis and being aware of *Headspace* on line, I dipped in and out of them, throughout treatment

When you feel you're on borrowed time, it's hard to be upbeat but if you look for the positive, it usually does help.

The hospital also has a Relaxation Group, you can be referred to Haven Breast Cancer Centre, which we're so lucky to have in Hereford, otherwise it's in London or Leeds - they are on hand to fill the gaps, have counselling, therapy, make up sessions, bra fittings or Yeleni Therapy & Support for health and wellbeing of all cancers, not just for the patient but also the family and carers.

Again, I found these sessions helpful, you don't have to explain anything, they know what you're going through at all stages.

There's also HOPE Support Services, Ross, for children of cancer patients, which is popular for on line help, for those that don't want traditional face to face help.

When the acute treatment ended and I can never thank all involved enough - that's when it hit me - I'd survived cancer but it's far from over when the treatment ends, a rollercoaster of emotions, what happens next? Well, you still have appointments, but you go from the intense almost daily contact with the medical teams to every few months, to manage on-going side effects:

hot flushes, fatigue, sleep disturbance, changes to heart and lung, brain fog, painful joints, nerve damage, lymphoedema and fear of recurrence.

I've spoken with many survivors who struggle with guilt in remission, triggered by reminders that are all around us in everyday life, in the media or on hearing of someone else's diagnosis.

All the sessions taught me to put myself first, which I struggled with but it's like on an airplane, you must save yourself first, to be able to help others. Mothers tend to put themselves last and it gave me the opportunity to breathe, to start de-cluttering not just physically, with crates of possessions, so family don't have to in the future, to embrace a routine, make a healthy eating plan or simplify your wardrobe.

This is when to make use of all the support that is out there, if you want it, it doesn't suit everyone but the hospital with their conventional care seems to be linking with the alternative options, at the therapy centres I've mentioned, Herefordshire Council with Change4Life (it's worth investigating the dangers of sugar) and Hereford move walking groups (for exercise and laughter) that are free or for a small donation.

It also helps to be practical for the future, put affairs in order, make a funeral plan - would anyone know your wishes? Family often don't cope well with feelings and want the person back to normal.

Make a Will, again Alison at MacMillan Info and Support can help you with financial and other advice.

Make a realistic bucket list - afternoon tea, attending a concert or having a spa day, go back to work, although you are expected to pick up where you left off.

Value time and energy, decide what you want, deserve and need, seeing a cat or a squirrel would brighten my day, notice how green the grass is ...

DP, April 2019.

Appendix 2:

A gentleman who was unable to attend the session wanted to highlight the following to the team:

“Had prostate cancer about 9 years ago and had treatment at Redditch, when he went to have his catheter out, nobody told him about having to wear briefs not boxers (with boxers you can’t put pads in) and it ended up wetting through in the waiting room.”

Appendix 3:

Breakdown of focus group

3 facilitators

8 Attendees

8 feedback forms completed

Female 3

Male 5

People who are family member or friend of someone with cancer 1

Number of people who have had a cancer diagnosis for:

6 months - 2 years 1

2-5 years 4

5 years or more 2

Age

46-55 2

56-65 2

66-75 2

76-85 2

