

Cancer Café Report

Held on 14th September 2015

Background

Cancer care in Southend is one of Healthwatch Southend's priorities in 2015. Together with the Macmillan Information and Support Centre we held a Cancer Café to find out the experiences of people who have used the cancer services locally.

Both Healthwatch and Macmillan Information Centre promoted the café by handing out leaflets, putting up posters, and talking to or emailing people who may be interested. It was held at the Southend Association of Voluntary Services (SAVS) in Alexandra Street and there was a great turn out of over 25 people and one of the Macmillan Information Centre's volunteers very kindly provided cakes for the café.

Healthwatch Southend opened the meeting by saying a little about what we do, and that we would be taking the information the users gave us and presenting it to stakeholders of the cancer services at a later date. Friederike Englund (Fred) from the Macmillan Information Centre then explained that she is really keen to make sure they are providing the correct services that people need and went on to say some topics she knew could be an issue for people are:

- Emotional issues
- Physical symptoms
- Relationship difficulties
- Practical issues
- Sexual difficulties
- Support for children/carers
- Spiritual issues/questions about faith
- Work and welfare
- Money worries and benefits

We then split up into four smaller groups and had discussions about the topics Fred had raised, and also about any other experiences people had, both good and bad.

Below is a summary of the concerns people had which covered a great variety of topics including: emotional support, communication, and parking at the hospital.

Although there were a lot of concerns raised it was very heartening to hear so many positive comments about the clinical side to the cancer treatment in Southend, and also the huge amounts of positive comments the participants made about the surgeons and the cancer nurses and they should be congratulated on their dedication. There was also a lot of positive feedback regarding local cancer support groups.

Comments and Feedback from Participants

1. What are your experiences?

Significant physical consequences of treatment: loss of taste- food no longer enjoyable, peripheral neuropathy making walking difficult.

Emotionally, constant fear of cancer returning, it's always on the back of your mind

Daily injections - major impact on life

It would be easy to give up, always need to push yourself

I couldn't survive without my wife; it would be terrible to be on your own

Appearances are deceptive, I look OK but I am always waiting for someone to tell me how bad I look.

When someone asks if I am OK I just say yes.

Cancer wards and staff are brilliant but there is less empathy and less notice is taken of dignity when sent to departments that don't only deal with cancer, for example when sent to cardio you are made to strip in a big room, no offer of something to cover you up when you're feeling very vulnerable.

The breast care nurses are brilliant, there are not enough of them, they leave and aren't replaced, and they do so much for us!

2. What one thing would you change if you could?

Having more energy, more interest in life

Not feeling cancer treatment is controlling my life

Important to promote well-being

Appropriate advice and information about the possible consequences would be very helpful; I was not prepared for this.

Appropriate aftercare, there is nothing!

More awareness so other people are less awkward around me, and don't say the wrong thing.

The treatment process - being treated as a new patient each time.

The parking at Southend Hospital!!!

3. Finishing treatment is often a very difficult time. Do you think supportive events should be routinely offered?

Family and friends don't understand, unable to talk about it with them

It is very isolating if friends now avoid you

Difficult to return to work as manager unaware of changing needs
Yes Sylvia Young (counsellor) is fantastic; I wouldn't have survived without her.
She's great, I saw her years ago.

4. Is talking about your cancer difficult? What would help?

Family and friends do not want to talk about the cancer; some friends have not been in touch since diagnosis which is very hurtful.

Brother can't acknowledge the cancer at all.

Friends will bring me to the hospital for treatment and appointments but won't talk about the cancer.

Talking helps, it is difficult but it needs to be done to help yourself and others.

5. Is asking family and friends for help difficult? What would help?

I am coping well currently; I don't need to ask for help

It is exhausting to always avoid friends and family because of coughs and colds, friends can't understand that a cold could be fatal; this has a massive impact on my social life

More awareness needed for them to stop those saying things that add more pressure

6. What about the effect on children and teenagers at home? Where you prepared for this?

My brother's children were not told how ill he was, children are very knowledgeable, and they will come to their own conclusions.

It is really important to talk to children very openly. I now don't worry about silly things; my children have picked up on this

My children do not talk to their friends about my cancer, there is a real stigma.

It was hard for my kids; they felt helpless to make things better for me.

7. We often hear that communication from the hospital and clinicians is unreliable, did you experience this?

Poor communication between the hospital and the booking team.

NO communication between the hospital and the GP, another user reported very good communication between hospital and GP

Yes after five years I was no longer a patient, when the cancer returned the clinic had none of my notes as I was now seen as a new patient - this took more time.

You see different staff all the time so a lot of repeating details.

8. Did you receive enough information about the next steps of treatment/ follow-up/screening?

I had a very clear plan in place

Treatment summary has been very useful for me and my GP

Not especially, there needs to be a change in the way things are done, like a drop in for existing patients rather than waiting weeks for new referrals.

I wasn't encouraged to contact nurses or doctors between appointments if I had a problem but others were, should this be communicated better?

There should be more promotion of support groups in the communication, they are invaluable!

9. Looking at the list of concerns on the survey sheet, would you like to talk about any of them.

No issues for me

Physical symptoms +++ for three participants

Finance was a nightmare, lost most of income.

It was difficult getting correct info about benefits; the DWP weren't forthcoming and wouldn't say what I was entitled to.

Other comments:

- Going back to work colleagues came up to me and said, yes I had cancer too
- There should be more information about how many cancers are cured!
- Prescriptions - too many tablets re-issued which are not needed, that is a waste
- Clinicians do a good job
- Infusion unit on KH is far too crowded
- Reception staff in chemo or oncology not truly aware of their importance as the first port of call for a patient and a relative. The anxiety of chemo/commencing any treatment heightened and reception staff first people they encounter.
- Not aware of the support groups available to access.
- System for seeing different consultants difficult, if under care of a surgeon and oncologist 2 very different views expressed at different appointments. Are aware of MDT but when see the consultants are given 2 different outcomes (usually one positive and one negative). Described as 2 different cultures operating separately.
- Would like access to what support available once treatment has completed, not aware of support available.
- Discharge home (for end of life care) positive experience and fully supported although a little like "Piccadilly Circus" with regards to nurses and carers.
- No support with regards to returning to work once treatment completed, not prepared for how difficult this could be.
- No information at diagnosis about diet and how to help yourself. Communication was vague; one patient asked if she could return to swimming following her axillary clearance to be told in a little while, not clear or constructive.

- Many comments about parking, the cost of it for the patient and visitors at a time when income is probably reduced or stopped, spending more on parking as kept waiting over an hour for appointments, stress of trying to park.
- Are people aware Macmillan has a Welfare Benefit Service?
- Family members don't get enough support, there should be something aimed at your support network, at the moment it's only specifically 'carers' who get support.
- There should be more resources for care plans; everyone should be treated as individuals.
- Support groups can apply for a Development Grant for up to £3,000 to help develop the groups including for social events, groups should be made more aware of this.

Next Steps

Healthwatch Southend will write to Southend University Hospital NHS Foundation Trust and NHS Southend Clinical Commissioning Group to share this report with them.

We will organise a public meeting to discuss what we have learned, and we will invite both organisations to attend. We will also extend invitations to everyone who we met through our work to produce this report.

We will publish details of the event on our website, and promote it with the public to capture the broadest range of views and experiences that we can at the meeting.

Healthwatch Southend would like to thank the Macmillan Information and Support Centre at Southend University Hospital for joining us in making the Cancer Café happen, and both we and Fred from Macmillan would very much like to thank all the women and men who have been so open with us about their experiences, it has been a privilege to listen to you all.