healthwatch
Dorset

Right by You:
What would you change about local cancer support services in West Dorset?

In partnership with

MACMILLAN
CANCER SUPPORT

Contents

Page

Part 1

Part 2

Part 1

Executive summary

Summary

Wessex Cancer Alliance, supported by Macmillan Cancer Support, are testing an integrated care model to improve the effectiveness of assessments and care planning for people affected by cancer. To evidence this Macmillan Cancer Support asked Healthwatch Dorset and Healthwatch Southampton to carry out a baseline engagement to find out people's current experience of getting support, what worked well and not so well.

This was done through an online survey (105 responses in Dorset) and 37 face-to-face interviews in Dorset during January & February 2020.

Most of the people Healthwatch Dorset spoke to are cancer patients or carers/family members. The majority of people who took part are aged between 55-74, identified as female and White British. Through our engagement we targeted areas of deprivation in Weymouth/Portland.

Headlines

- People we spoke to in Dorset were happy and grateful to the NHS for their medical treatment.
- Almost 60% of online respondents had had a conversation with an NHS professional about their support needs, compared to around 40% of the people we interviewed face-to-face.
- People affected by cancer would like more support throughout their journey, particularly around emotional support, with treatment, finances and transport.
- There is less support available for some groups, for example, younger cancer patients, carers and family members.
- People are seeking and developing different support options in their local communities.
- This baseline work has allowed for a greater insight of what matters most to people affected by cancer providing a platform for the Right by You pilots to build on.

This quote is about the emotional support people would like to receive:

> "Being able to share my worries with someone who is experienced and able to listen and offer ideas and advice."

Key recommendations:

- People would like to see a range of good quality individualised support provided in community settings and at hospital, throughout their journey, including after treatment. This support should be close to home and easily accessed 24/7.
- Scope and map support available to improve signposting, developing robust ways to promote and make it easy to access existing information about the wide range of national and local cancer support groups across the area.
- Review current models and develop opportunities for people affected by cancer to share experiences and find solutions on the issues that matter to them.
- Proactively review feedback from and engage with seldom heard groups to inform the pilot and evaluate the experiences of people with 'protected characteristics'.
- The need for carers to receive support and information should be recognised.

Part 2

Introduction

Macmillan Cancer Support and the Wessex Cancer Alliance approached Wessex Voices, Healthwatch Dorset and Healthwatch Southampton to carry out a piece of engagement with existing cancer patients, their carers and wider family. They wanted to use the information gathered, to inform two 'Right by You' pilots planned in Southampton City and West Dorset, which aim to provide people with support in the community earlier in their cancer journey.

Wessex Voices, an innovative partnership between NHS England and five local Healthwatch organisations in the Wessex area, carried out a literature review in preparation for this project. This is available on their website:

https://www.wessexvoices.org/uploads/9/2/1/6/92161062/right_by_you_literature_review_-_october_2019.pdf

What we did

We designed a project that gathered feedback through 1:1 interviews and an online survey. We produced leaflets and posters, alongside social media promotions and press releases to promote the project:
https://healthwatchdorset.co.uk/how-would-you-improve-local-cancer-support-services/

Who we spoke to: face-to-face

Healthwatch Dorset carried out 37 face-to-face interviews across Dorchester, Weymouth and Portland. We visited the following venues and groups:

- Butterflies Support Group, with one of our volunteers
- C'Siders Support Group, with Tracy Street from Macmillan Cancer Support
- Dorset County Hospital FT Chemotherapy Unit, with one of our volunteers
- Purbeck Workshop, with one of our volunteers
- Royal Manor Health Centre, with one of our volunteers
- The Bridges Medical Practice
- Stalbridge Surgery, with Tracy Street from Macmillan Cancer Support

Who we spoke to: online

More woman (54 people), than men (23 people) took part in the interviews; 27 people left this unanswered. The majority of people who took part:

- were aged 55-74 years (45 people)
- were cancer patients, or carers/family members
- described themselves as White British ethnic background (74 people)

Our volunteers

We had two volunteers who helped with the interviews during this project. Their involvement was invaluable. Both volunteers have had their own personal experience of cancer. They volunteered approximately 20 hours of their time to help.

> "It was lovely to meet such friendly, interesting people who were so positive about their illness and that of their loved ones. They also commented what good work Healthwatch was doing in this field." **Hazel, Healthwatch Dorset volunteer**

What people told us

Interview findings

The first question that we asked people was whether they had a conversation with an NHS healthcare professional about their support and needs around cancer. 59.4% (22 people) of the people that we interviewed said they had not had a conversation about receiving support, and of those people 95% (35 people) said that they would have benefitted from this.

Of the 40% (16 people) who did have a conversation with an NHS professional, it was mostly at hospital, or with their GP. The people that we interviewed preferred to have this conversation at diagnosis, but the setting they would prefer gave mixed feedback.

Nearly all of the people we interviewed said that they were very happy with the medical treatment that they received. However, they would have liked more emotional support, and advice around diet and exercise.

> "At diagnosis, as you need help to process it. I would just like to talk to someone, as you get told and then you are sent home. I would have liked some emotional support."

- People told us that they would like to have received emotional support in the hospital, or in local community/support groups.
- The carers who took part in the interviews said that they were not given enough practical help or emotional support around how to care for their loved one.
- A few people said that when they were diagnosed, they were in shock and were unable to take anything in. However, they would have liked support during their treatment.
- Some of the people who didn't receive any formal emotional support, were very grateful that they received support from their family and friends. They did, however, appreciate that this was not the case for everyone.

Case studies

Case study 1

A man we interviewed said that he did not receive a conversation with an NHS professional about his support needs but would have liked to have received emotional support during his treatment, as he found that to be a very stressful time. He received a lot of help from his daughters and help from friends instead and found support from attending church and community groups. He is a retired GP and was practicing for 50 years. He said that people seem to assume that you don't need support because they think you know everything about the condition and treatment. He also found that his diagnosis and treatment wasn't explained to him because he is medically trained. He felt that he needed support, the same as any other person who was going through that would.

> "Because I am a retired GP, people assume that you don't need any support or information."

Case study 1

We interviewed a woman who said that she would have really benefitted from emotional support during her cancer journey. She would have liked to have had access to a Macmillan Nurse, someone to explain what was going on and how she would feel during her treatment. This person lives alone and would spend all day travelling on a bus and a train to have her treatment. She would have liked some help or advice with regards to transport. On one occasion when she was travelling on a train with a line in her arm, someone accidently bumped into her and she passed out on the train. The only support that she received was from a counsellor after she had fully recovered and was suffering from anger, fear and depression. She has since found support from the C'Siders Support Group.

> "I still feel traumatised and frightened by the lack of support."

Case study 3

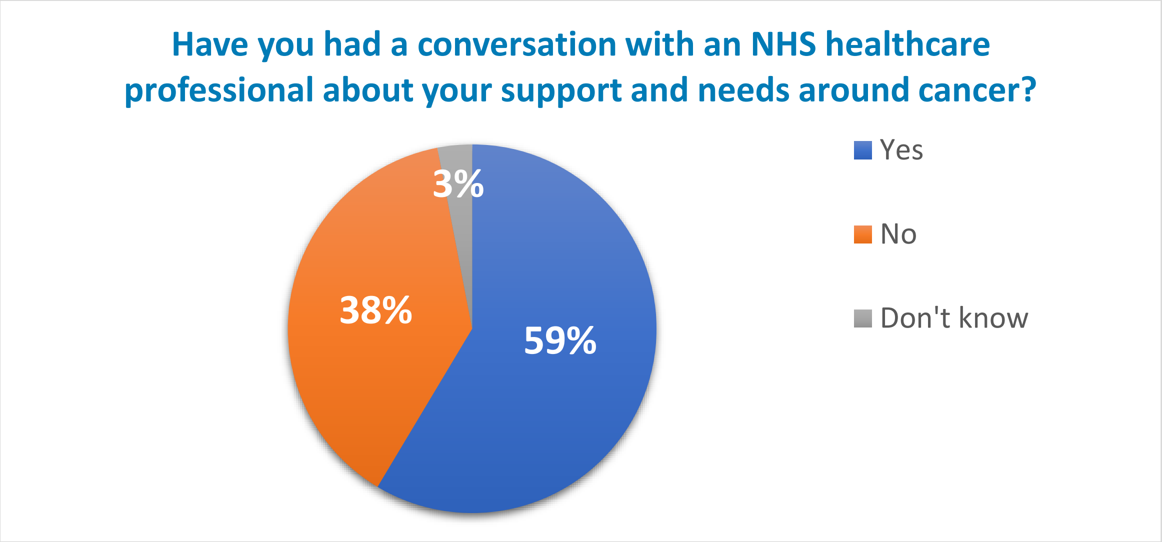
We spoke to a woman whose husband was diagnosed with cancer. She said that at diagnosis they had a conversation about their support and needs around cancer. The conversation took place with a Macmillan Nurse present who immediately passed on her contact details. The conversation covered everything, particularly emotional support from the Macmillan Nurse. She said that their cancer support and treatment could not have been improved in any way.

> "It was almost a pleasure to have a problem, a lovely journey, if it wasn't for the fact it was cancer."

Online survey findings

The next section of the report will explore the online survey findings and will show similarities and differences with the face to face interviews. The online survey showed more positive findings, and these will be explained below.

Cancer support

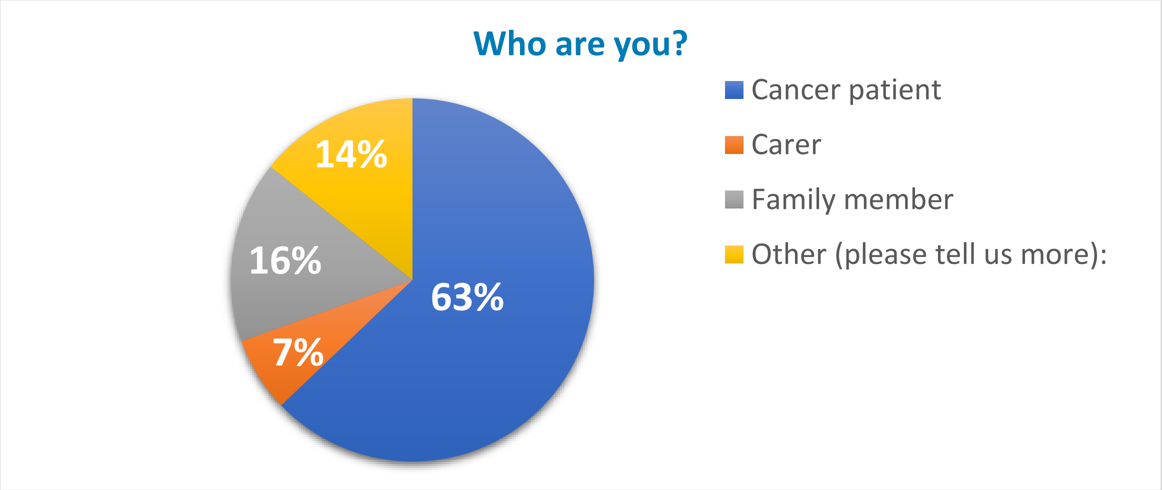


The online survey results show a majority of respondents having talked about the cancer support care services with a healthcare professional, 59% (58 people).

Number of respondents:

- Yes: 58
- No: 38
- Don't know: 3
- Total responses: 99

Respondents

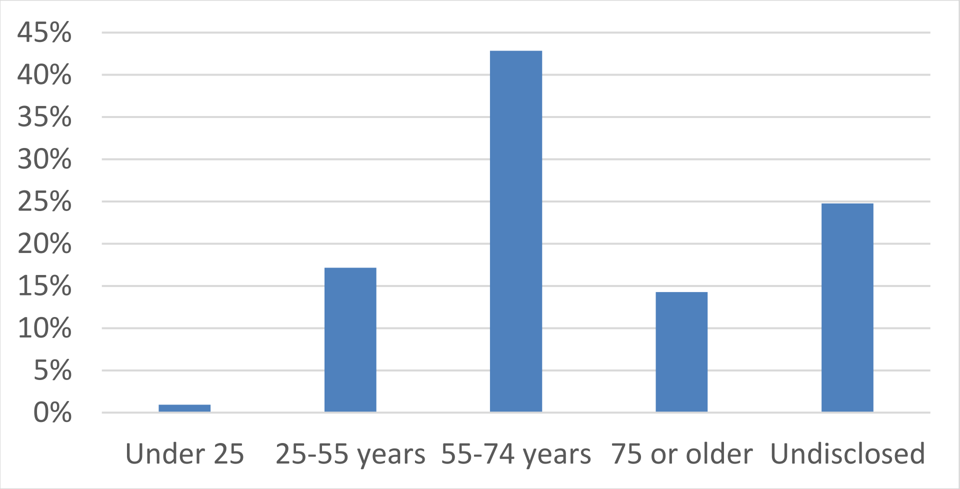


Most people who took part in the online survey were themselves cancer patients, 63% (66 people).

Number of respondents:

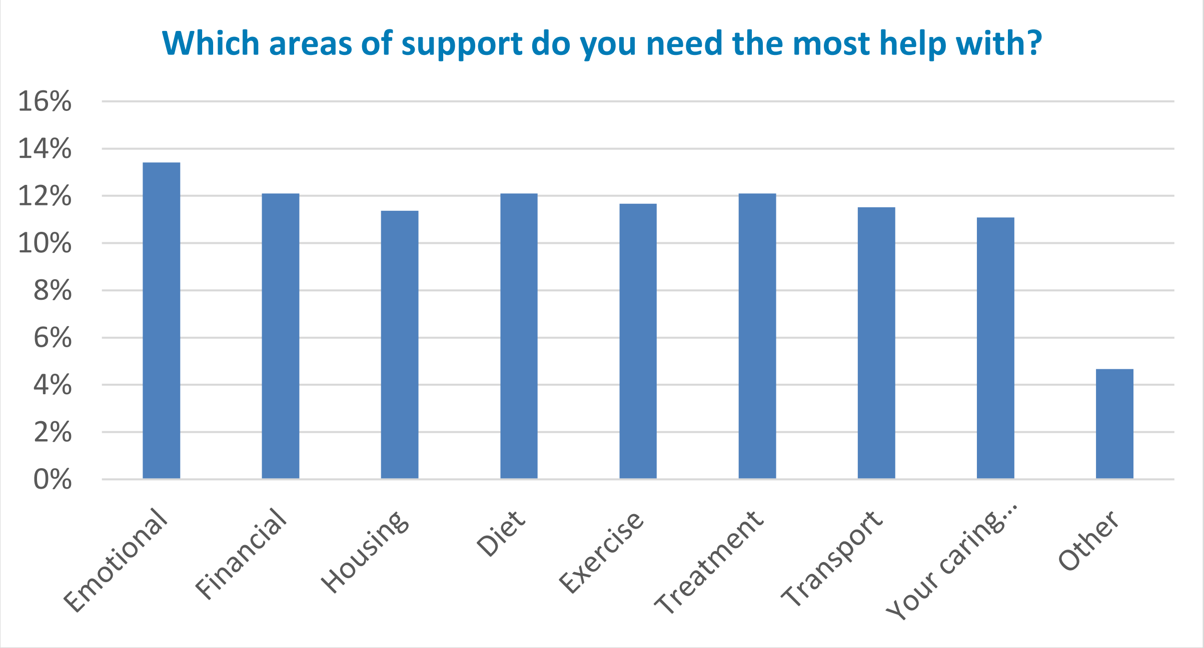
- Cancer patient: 66
- Carer: 7
- Family member: 17
- Other (please tell us more): 15
- Total responses: 105

Age range



The graph above shows the age range of the survey respondents.

What support is felt to be most needed



Number of respondents:

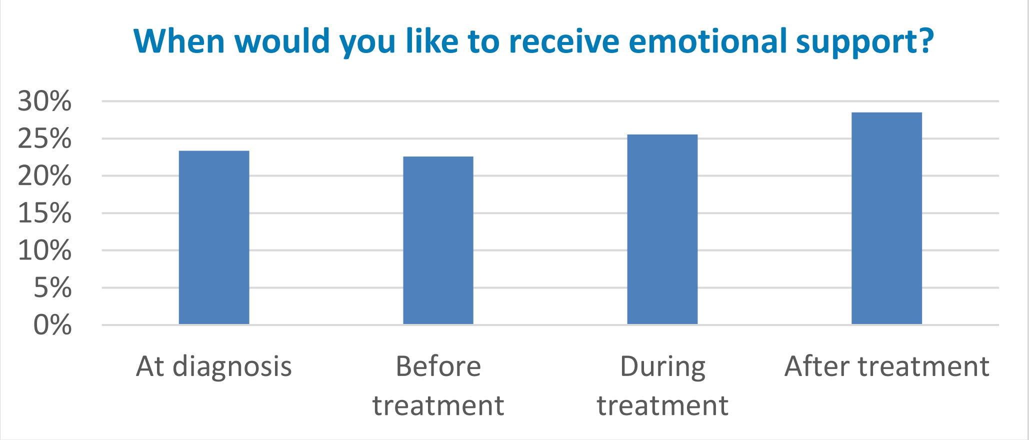
- Emotional: 92
- Financial: 83
- Housing: 78
- Diet: 83
- Exercise: 80
- Treatment: 83
- Transport: 79
- Your caring responsibilities: 76
- Other: 32
- Total number: 76 (this is the average of all responses received across the nine responses as people could select multiple responses for this question)

For each of the areas of support in the table above, people were asked to say how they rated them in terms of importance.

The top five (in order of highest to lowest) support categories which our online survey participants felt was most needed when going through cancer support care were; emotional, treatment, financial, diet and exercise. Emotional support was rated the highest.

The next section explores specific types of support and the time of when the support was wanted, for example, at diagnosis, before treatment, during treatment or after treatment.

Emotional support:

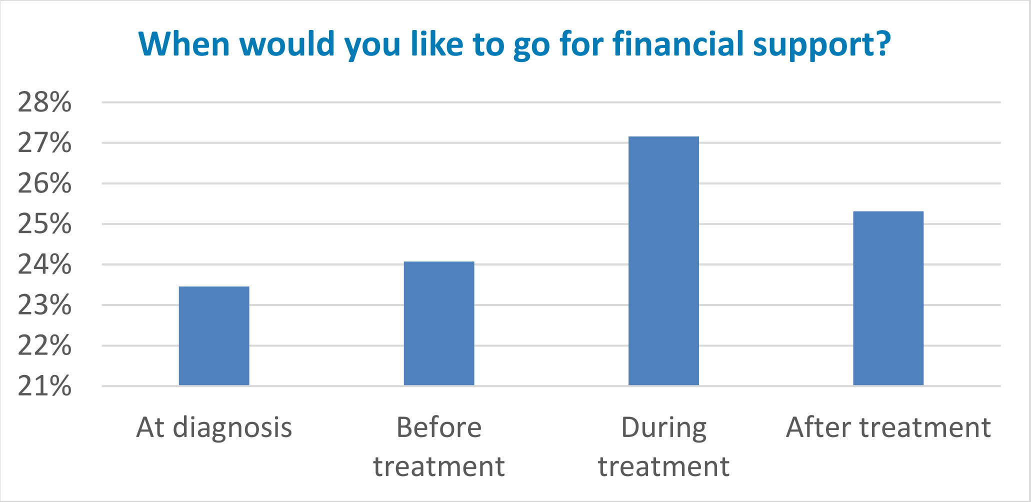


As the graph above shows, people felt that they needed emotional support throughout their cancer journey, with slightly more people saying that after treatment it is particularly more important. When asked where they would like to receive emotional support, people told us that they would prefer to receive this through community support groups.

> "It would be useful to have someone to talk through what we are going through with my dad's terminal cancer, what is to come etc."

This result is supported by the face-to-face interviews.

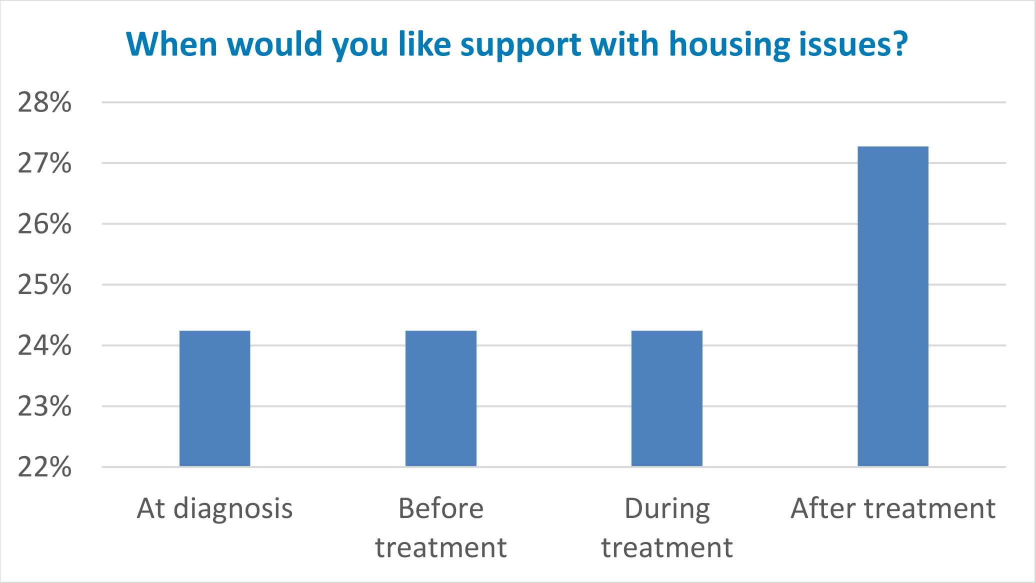
Financial support:



This quote from our online survey shows the financial impact of living with cancer.

> "Due to the side effects of the medication and general fatigue I have had to change from working full time in a well-paid professional role to a part-time role with an agency which pays less than half my previous salary. Yet my mortgage and outgoings have stayed the same."

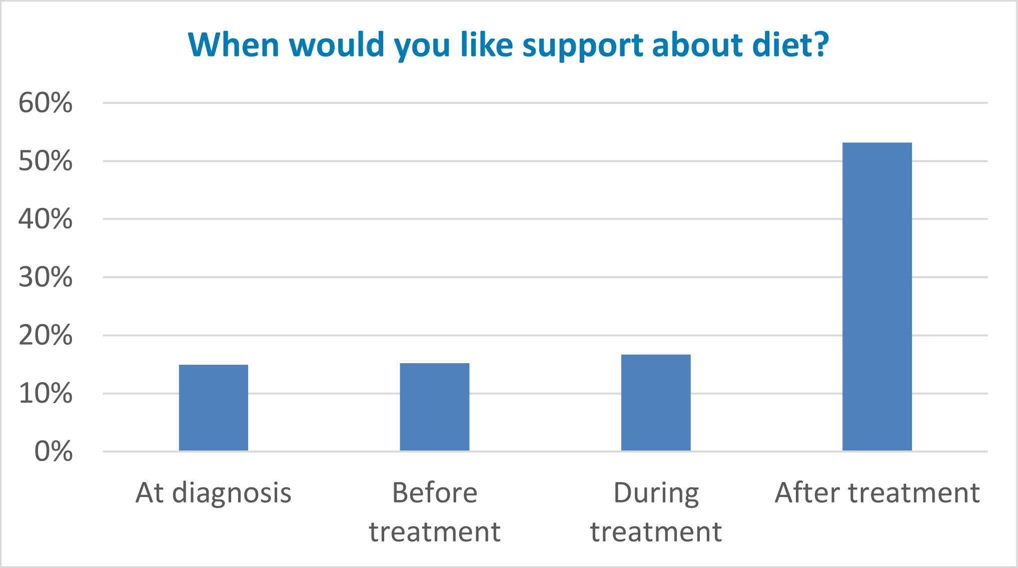
Housing support:



A cancer diagnosis can have a widespread impact on many aspects of someone's life, as illustrated by this response that we received:

> "I am currently in the middle of moving house, as I can no longer afford to pay all the bills. I am not only downsizing but I have been forced to move to a different county in order to be able to afford a suitable property. This means that I will have to change my GP and attend a different hospital."

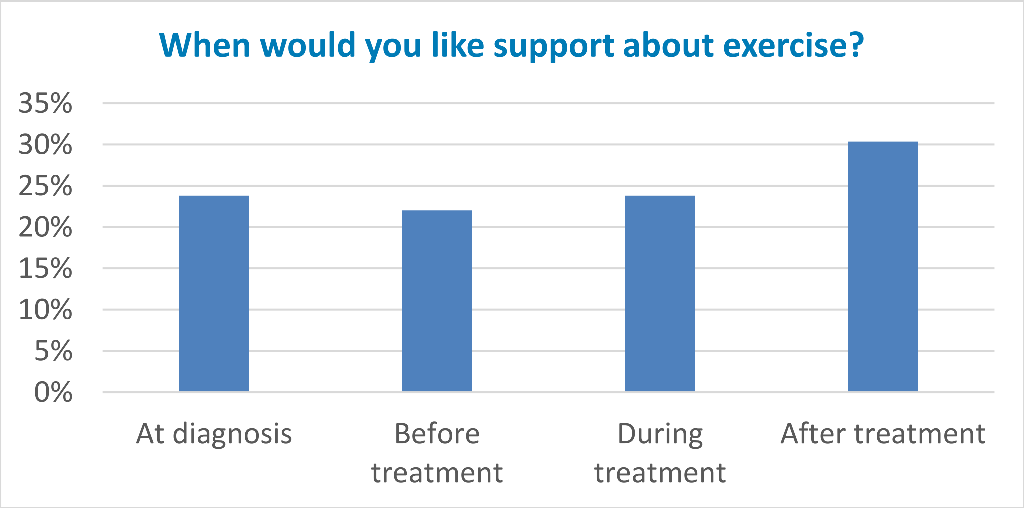
Dietary support:



This quote from our online survey emphasises the need for more support about diet, especially after treatment:

> "As my treatment is ending now I would like to lose weight though not sure of the most healthy way to do this as I have radiotherapy fatigue. A personalised diet plan would be very helpful."

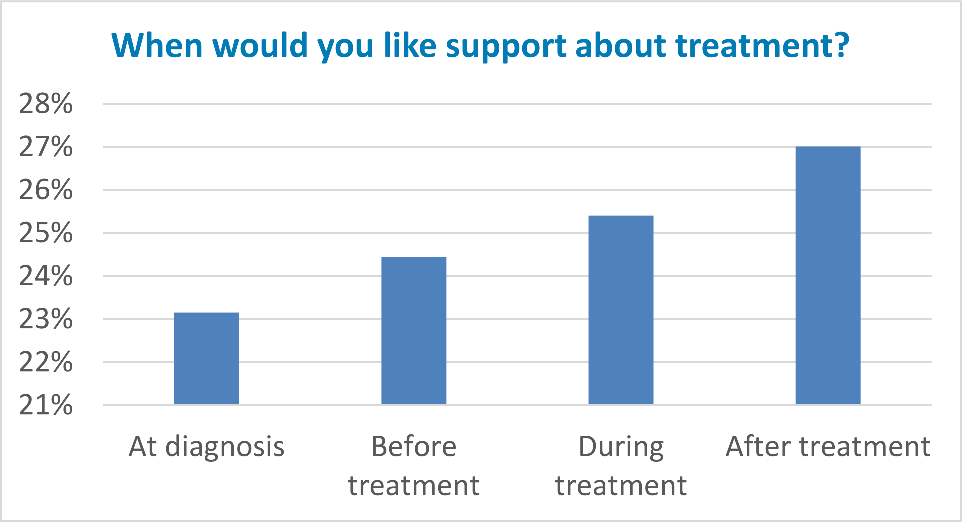
Exercise support:



People would like support about exercise throughout their cancer journey. This quote shows that people want to receive personalised information about exercise:

> "My dad has been told to keep active to help his bones etc., but again no support offered. As an older man who has never done anything more than walk, some support and guidance would be useful for him as he doesn't know what he should be doing!."

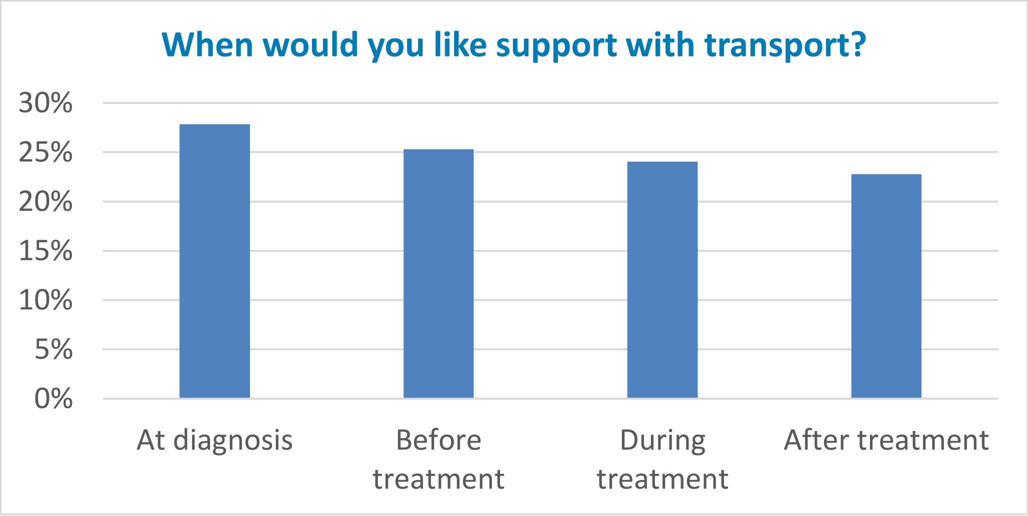
Treatment support:



Support about treatment was mostly wanted during and after treatment, respondents requested more aftercare support as this quote shows:

> "I needed more aftercare - especially when in remission. It seems that once treatment has finished you are just left."

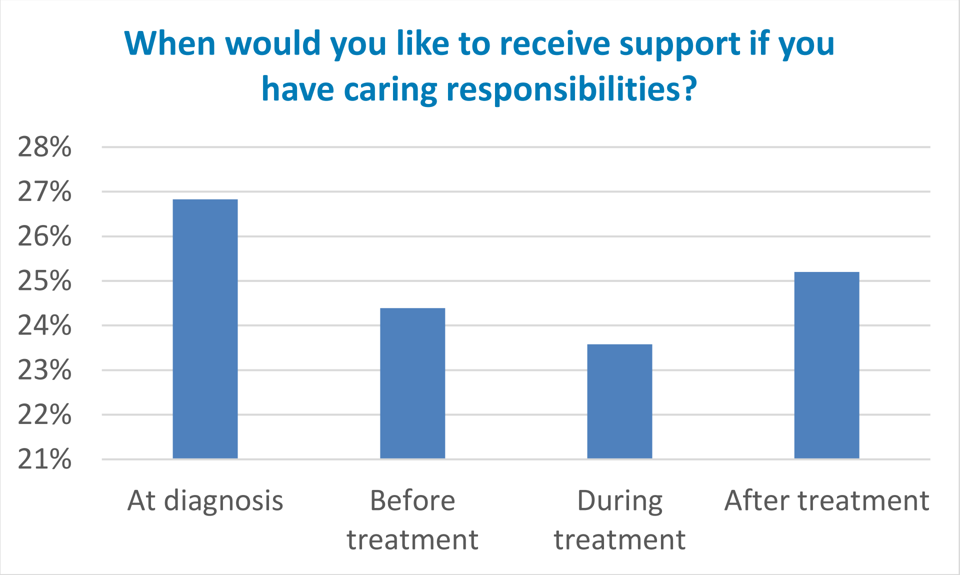
Transport support:



People feel transport support is needed throughout their cancer journey, as this quote shows:

> "There is no transport to enable people to get to hospital and public transport is virtually non-existent. For example, there are no buses to get you to hospital for an operation which is scheduled early in the morning."

Caring support:



Our online survey showed that carers would like to receive more support from diagnosis, as this quote explains:

> "I didn't know who to speak to, or what to ask. We just did our best to go about life as best, and as usual as we could. Put a 'brave face' before our family and friends.
>
> "Would be useful to talk to others who are going through or have been through the same experience for support and advice. In addition, I am trying to support my parents alone, whilst having a long-term condition myself and working full-time. It is very stressful and difficult trying to juggle it all with no help or support myself. I do not have a partner or children, so it all falls to me to do everything."

What does good support look like?

In our online survey we asked what good support looks like to people who are living with cancer. Survey respondents provided us with many examples of the good local support they'd received. For example:

> "The care nurse from Forest Holme Hospice gave us both wonderful support. Anything we thought might be helpful and useful in the way of equipment was with us within a couple of days. Attendance allowance and disabled parking were with us without any

paperwork or fuss. When time came that I could no longer cope with my wife's care she was in Forest Holme within hours."

"MENTalk at AFCB has helped my husband immensely."

"The support from Weldmar at diagnosis, Macmillan and the CAB for the emotional and financial side of things has been a great help to say the least. Post operation, Stepping Out / Living Tree in Bridport are an amazing resource to get fit after the operation and keeping me that way both physically and mentally."

What type of support would you like and where?

We received many suggestions for types of support and venues. People told us they would like more variety in the types of support available, during evening and weekends for people who are working.

Types of support:

"More evening and weekend support groups and wellbeing activities."

"Physiotherapy post operation, relaxation therapies, advice for better sleep, facilitated coffee morning group for patients with a structure for discussion and support."

""Everything is in work time, and for my husband who unbelievably is managing to stay in work, he is unable to attend any of the sessions run locally like the wellbeing sessions etc."

"When I'm undergoing treatment, it is very difficult for me to look after my children or to walk my dog. My side effects don't last long but it would help greatly to have some sort of consistent community support, so I don't have to rely solely on friends or having to pay for services as my finances are stretched to the limit. I'm a lone parent with no family nearby."

Venues:

"Leisure centres, libraries, village halls, church halls, rooms available in supermarkets, GP practices where there is lots of space, cafés etc."

"Community hubs could be based at GP surgeries. They would need to be accessible and the environment should be warm and welcoming. They could be offered in hotels but need to respect patient confidentiality."

"Local health centre, café or pub."

Conclusion

This project has highlighted possible areas of development for local support cancer services. Healthwatch Dorset has made a number of recommendations:

Full recommendations:

- The most common concern that people raised with us was the need for more emotional support during their cancer journey. People would like to see a range of good quality individualised support provided in community settings and at hospital, throughout their journey, including after treatment. This support should be close to home and easily accessed 24/7.

- We spoke to people who really appreciated the help they get from cancer support groups in West Dorset. We recommend that the NHS actively scope and map support available to improve signposting, develop robust ways to promote and make it easy to access existing information about the wide range of national and local cancer support groups across the area.

- Review current models and develop opportunities for people affected by cancer to share experiences and find solutions on the issues that matter to them. For example one suggestion that we received was:
  "I used the cold cap, which really helped with my mental health. That needs to be promoted a lot more, as I was only told about it from a friend."

- Proactively review feedback from and engage with seldom heard groups to inform the pilot and evaluate the experiences of people with 'protected characteristics'.

- The need for carers to receive support and information should be recognised.

Next steps

Our project results include many recommendations for types of support and community venues where people would like to get support during their cancer journey. We will now share our findings and work with the pilot projects to help create more person-centred local support.

Acknowledgements

Healthwatch Dorset wants specifically to thank our Healthwatch Dorset volunteers, Butterflies Support Group, C'Siders Support Group, Chemotherapy Unit at Dorset County Hospital Foundation Trust, Purbeck Workshop, Royal Manor Health Centre, The Bridges Medical Practice, and Stalbridge Surgery. Without their support the public engagement numbers on this project would have been considerably lower. We also want to say a thank you to anyone who participated in this project. The public engagement touched upon some sensitive topics and for the Dorset general public to engage and talk about those topic's, we are truly grateful. This gave us a good insight to what works well and what can be improved with cancer care support services.

Appendix

Lessons learnt from engagement process

If we were to undertake the engagement exercise again, there are three areas we feel that would need to be addressed.

Firstly, about the questionnaire design. The carer and family response category was confusing for some participants. People were not clear whether they could, or should select one, or both depending on their situation.

There were more positive responses on the online survey than through the face-to-face interviews when we asked if people had had a conversation with a healthcare professional about their cancer support needs. This could be because people felt that they could talk more freely and openly during a one to one interview which shows the benefit of using a mixed methodology.

Most of the people who took part in the study identified as female and of white British ethnic origin and therefore are likely not representative of the more diverse population across Dorset. Other issues like gender, disability, sexuality and specific issues like fertility also needs to be considered in offering support to people so further investigation of existing patient and public feedback and engagement on these issues may also be necessary.

Carrying out the face-to-face interviews was a very interesting, and an enlightening experience. I met a lot of people who were very positive about the medical treatment they received, and I learnt a lot about what support is available to people in the community. The individual interviews took a lot longer than I anticipated, as people were very happy to talk about their own, or their friends/families experience. People wanted to provide their feedback and were all very supportive of this project. Some of the interviews were quite emotional, as a few of the people that I spoke to were still receiving treatment and were feeling scared and overwhelmed. I found that the Dorset County Hospital Chemotherapy Unit worked very well with regards to carrying out the interviews. The support groups were also a good environment, as the people who attend were used to talking about their cancer journey. One person who attends the Purbeck Workshop said, “since coming here I have gained a lot of support, and I can now offer support to other cancer sufferers.”

One of the things that did come as a bit of a surprise was how helpful the British Red Cross have been to a couple of the people who I interviewed, one person said, “British Red Cross have been amazing, helping me to travel. Marvellous!”

Lucy Cribb, Healthwatch Dorset Engagement Officer

This page is intentionally left blank

☎	0300 111 0102
✉	enquiries@ healthwatchdorset.co.uk
🌐	healthwatchdorset.co.uk
✎	The Bridge, Chaseside, Bournemouth BH7 7BX
f	@HealthwatchDorset
🐦	@HWatchDorset
◎	healthwatch.dorset
in	healthwatchdorset

The Healthwatch Dorset service is run by Evolving Communities CIC, a community interest company limited by guarantee and registered in England with company number 08464602.

The registered office is at Unit 4 Hampton Park West, MELKSHAM, SN12 6LH.