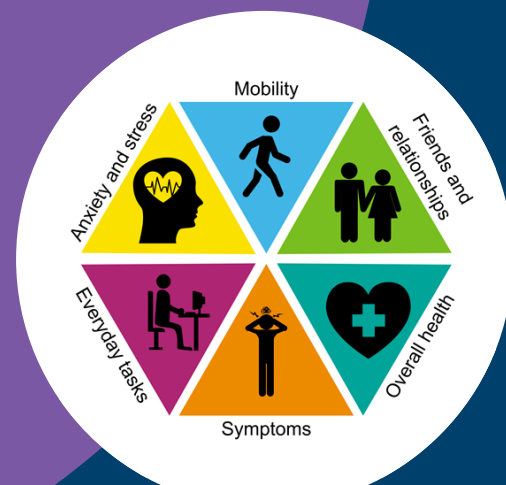


The Problem

The effect of a cancer diagnosis and its treatment can have a significant impact on a person's physical, emotional and social wellbeing. The National Cancer Quality of Life Survey is sent to people 18 months after diagnosis and the findings can be used to guide service improvements. The Peninsula Cancer Alliance (PCA) was asked to identify a quality of life priority for local intervention by the NHS National Cancer Team. Difficulty sleeping was a symptom reported by all cancer types (25.1%) and was therefore chosen as an area for intervention. The PCA has consistently maintained a >50% response rate since its launch in 2020.



Mapping of Services

The team started by mapping current services available for people with cancer, across Devon and Cornwall and found:

- Specialist services within secondary care for sleep apnoea
- No specialist sleep services or pathways for cancer patients
- All Clinical Nurse Specialist and Support Workers offer sleep hygiene support
- All Cancer support Centre offer complimentary therapies, relaxation techniques and sleep hygiene support
- A TALKWORKS online Improving Sleep Workshop, but this does not include Plymouth and Cornwall patients. This is not a cancer specific course.
- The Sleepio App is a free Macmillan funded app available for all cancer patients in England. Sleepio is a 6-week self-taught programme. Awareness of this App was limited.
- Private clinics were available but at a cost.

TOP TIPS TO IMPROVE SLEEP

- ★ Move your body! It works better when it is moved, circulation is better, pain levels improve and it helps improve mental health
- ★ Don't eat 2-3 hours before bed, and don't eat in the night if you wake up
- ★ If you are tired you are drawn to higher fat and sugary foods, it makes you feel less like cooking and making healthy choices
- ★ Relaxation benefits you even if you are not asleep, find something you like to do to relax your mind and body
- ★ Getting up at the same time each day helps to build a healthy sleep drive
- ★ Go outside each morning, helps to regulate circadian rhythms - our natural body clock
- ★ Staying awake gives you energy to sleep!
- ★ Prepare for bed before you are thinking about going to bed so that the activities you do don't energise you
- ★ Don't worry about going to bed at the same time each night, go when 'sleepy tired'
- ★ Spend less time worrying about your sleep, spend more time enjoying your day

Interventions to Address Patients Difficulties With Sleep

Beth Kingshott Cancer Alliance Support Manager, Peninsula Cancer Alliance

Miranda Benney Centre Manager, The Mustard Tree Macmillan Cancer Support Centre, University Hospitals Plymouth

Focus Group

A focus group was held in Exeter Central library. People were invited who had received a diagnosis in the last 2 years. 6 people attended and they were asked to share their experiences. The Sleepio App was demonstrated to the group.

- Treatment makes sleep particularly challenging i.e. fatigue, toxicities and side effects.
- Would be useful to have resources in one place. Liked the idea of a Sleep Toolkit using a QR code.

- Sleep was managed with medication -anti-depressants or sleeping pills
- Some participants had used the following to aid them with their sleep; BBC Radio/ White Noise Machines/ sleep inducing pillow sprays
- No one had heard of the Sleepio App - but would try it after the demonstration

Following the mapping process and focus group the idea of hosting a workshop was formed.

Have benefited from complimentary therapies

Anxiety often overpowers sleep

When caring for sick husband slept well as was constantly on the go. Now since my diagnosis I have a 2 hour sleep routine.

Sleeping was particularly challenging throughout chemotherapy and months after.

Workshop Planning

- Offer two sessions to allow for flexibility and choice for attendees AM and PM
- City Centre location with good transport links/accessibility
- How to advertise - social media, clinical teams, Cancer Support Centers, Primary Care Networks
- Engagement with Stakeholders for promotion
- Key speakers -Sleep Expert/Nutrition/ Exercise/Relaxation
- Sessions to be interactive
- Resources - staff to deliver help with day
- How to best use Media Interns

Workshop Delivery

- 2 x 2.5 hour sessions
- 4 speakers
- Cost
- Participant interaction - round tables for peer support
- Practical sessions
- Capturing patient experience for sleep videos
- Exercise bands, fruit, sleep information handouts
- Market place of Support Services - e.g. Benefits advice, walking groups, cancer support centers



Email from attendee after event

I just wanted to pass my thanks on to the team. What a brilliant workshop this afternoon. The entire content was relevant and very supportive. Thanks to all for the warm welcome. The four presenters were brilliant, and I will take something from every session that will be supportive. I am ever grateful to the whole team for their holistic and considerate support



Challenges

- Administration of event
- Use of technology to reduce 'paper admin'
- Reaching those in hard to reach areas
- Patient and staff engagement
- Maintaining the momentum with advertising
- Availability of speakers
- Geography of Peninsula

What Worked Well

- The excellent speakers
- Running two sessions
- Carers were included
- Number of Health Care Professionals who wanted to attend
- The Mustard Tree Team 'Meet and Greeters'
- Everyone joined in with all sessions
- Working with the Media Interns
- Giving out exercise bands, fruit, handouts
- Using technology to organise guest list and feedback
- Market place stalls
- Sound bath demonstration
- Cost - approximately £3500 for the day - £45 a person
- 78 people attended in total

Bath Spa University Interns

In collaboration with Bath Spa University, the PCA had two Media Interns on placement with them for an academic year. The aim of their roles where to:

- Research, identify and create short video stories
- Aid the understanding of cancer services
- Help to demystify an experience many fear and to highlight the work of those who help

The PCA Interns identified Sleep as a project that they would like to create content for, aimed at providing some meaningful tips to help patients who are having difficulty sleeping.

The media created will be hosted on MySunrise Cancer Companion App and the PCA and Trusts websites.

Patient Evaluation of Workshop

An evaluation form was developed and accessed with a QR code to obtain feedback after the workshop and was also emailed to attendees. 27 responded. A further evaluation form was sent 8 weeks after the event to measure the impact with 13 responses.

What people found helpful

- Found it was very interesting, like to go to one of them (workshop) again
- I came away with good ideas to try from the exercise, physiologist & nutritionist
- In all found the day helpful
- I really enjoyed the sleep therapist. She talked a lot of sense
- Feel very grateful of timing of event and finding a sleep expert like Stephanie as had not managed to find any one myself as seem very rare and most advice online not detailed enough
- Very informative and the last meditation session was really relaxing
- I came away feeling there were options for me other than medication.

Please give a brief explanation of how you feel your sleep has been affected

Reflux	Stress	Nausea	Dry mouth
Intrusive thoughts	Chemo treatment	Bad dreams	
Depression	Broken sleep	Can't sleep	
Overthinking	Steroids	Pain	Night sweats

Have you been offered / received any support with sleep since receiving your cancer diagnosis?

Pillow support	This workshop	Sleeping pills
Medications	Mustard Tree	Antidepressants

Follow up - 8 weeks later



Next Steps

- Sharing the Evaluation Report with wider teams
- Promotion of the two films
- Explore development of sleep toolkit via MySunrise App and the PCA website
- To run the workshop in different locations - Barnstaple, Exeter, Torbay and Truro
- Work collaboratively with local groups, in particular social prescribers that link to the community and hard to reach areas
- Promotion of Sleepio App across the region
- Health and wellbeing training for professionals to support them with insomnia. A number of professionals wished to attend the workshop to help with their own sleep difficulties as well as to support their patients.
- Opportunities to work with the wider Personalised Care Agenda and other long-term conditions.



Sleep and Insomnia - Managing Difficulties with Sleep Exercise, Nutrition and Sound



Sleep and Insomnia - Managing Difficulties with Sleep Sleep Physiologist