

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Effaith yr ôl-groniad o ran amseroedd aros ar bobl yng Nghymru sy'n aros am ddiagnosis neu driniaeth](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on the [impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment](#)

WT 03

Ymateb gan: | Response from: Tenovus Cancer Care



Health and Social Care Committee - Short inquiry into the impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment.

Evidence submitted on behalf of the charity Tenovus Cancer Care by Judi Rhys MBE, Chief Executive

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No information in this submission is confidential. All case studies are anonymised.

Tenovus Cancer Care welcomes the opportunity to submit evidence on this important topic. We are the leading Wales-based cancer charity, providing practical and emotional support to anyone in Wales who is affected by cancer, at any stage of their cancer journey. We do this through a range of services, which include a nurse-led support line that operates 365 days a year and includes a unique call back service, the provision of benefits advice and a newly launched all-Wales counselling service. We have a peer-led volunteer telephone and befriending service, which was set up at the beginning of the pandemic. We run 16 Sing with Us choirs right around Wales, where those affected by cancer can receive social and emotional support in an understanding environment and experience the proven benefits of singing for health. We have four mobile support units that we have deployed for a variety of uses (described later) in communities. And we have funded a two-year clinical psychologist post, operating from and managed by Maggie's Centre at Velindre Hospital, Cardiff.

Please see below for more detail about how our services have responded/are responding to the needs of those affected by cancer since the start of the pandemic, particularly in light of the increased waiting times that people are experiencing at one of the most stressful times of their lives.

Clinical Advice

The Tenovus Cancer Care nurse led specialist support line provides advice, information and support for anyone affected by cancer. This helpline is available 365 days a year.

During the last year our Callback Service has been reviewed and adjusted to meet the needs of our clients and our partners in the NHS. We have liaised with our partners to ensure we provided support that was beneficial to the patients but also so that the NHS was supported by this service - to potentially reduce the number of calls coming back to secondary care because the advice and support accessed through Tenovus Cancer Care provided much needed reassurance to patients. The Callback service provides a series of calls for patients starting their cancer treatment over a period of 4+ months and longer if required. These calls include an assessment of need, explanation of possible side effects of treatment, reassurance on presentation of symptoms, advice on pain control and emotional support.

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We have noted a considerable increase in the need for emotional support over the last year from those worried about cancer, waiting investigation results, uncertainty and cancer related anxiety and distress.

Case Study

Ginny is just one of thousands of people we've supported over the years on our Support Line:

"I was being treated for fibroids which required a radical hysterectomy and it was only through the pathology notes after the operation that I discovered I had cancer. I had no idea beforehand and despite the symptoms it was a huge shock. I was added to a waiting list to have a scan and I got into a terrible anxious mess over it all.

I have a 15-year-old daughter, but I couldn't talk to her with a complete feeling of freedom because it would have been too much for her. Although she does love my honesty!

I didn't really have anyone close by. My mother passed away ten years ago, my brother was very supportive but lives near Ludlow and my sister hadn't been very well herself, so it was great to find information about Tenovus Cancer Care's Support Line.

I started speaking to a nurse called Elaine. After I'd made the initial call, Elaine would phone me every two or three weeks. She was incredible, and lovely to talk to. I was keen to know how I would feel with all the different types of treatment. I felt like I was having the book thrown at me and didn't know what to expect but Elaine was very knowledgeable.

I felt like our calls were a moment to sit down and reflect on where I was going and what I'd been through, and what was normal and not normal about it all. We also talked an awful lot about nature because we both have that interest in common! Using the Support Line allowed me to be open and reflect without putting any burden on my daughter."

Benefits Advice

Tenovus Cancer Care's Benefits Advice Service provides free, impartial welfare benefits advice and support to those with a cancer diagnosis. This ranges from carrying out benefits checks to identify eligibility for a range of financial help, through to full casework to assist in applying for and obtaining the appropriate benefits and grants. We also support individuals to challenge benefit decisions and to liaise with third party organisations on behalf of clients.

Throughout the Covid-19 Pandemic, the benefits team have had to adapt to the changing advice environment. This included advising on Covid-related grants and payments, and adapting our service provision to keep staff and clients safe. Where previously we provided face to face advice within cancer clinics, or at home visits in our clients' homes, we have adapted to provide a fully remote advice service. Advice is provided fully via telephone and internet communication with clients, together with using paper based methods where needed for form filling.

In conjunction with the changing processes of the Department for Work and Pensions, the way we provide documentation to the Department, processes for benefit applications and client identification processes all changed as a result of the pandemic.

Internal data based on Tenovus Cancer Care's welfare benefit client data appears suggestive of a trend in clients presenting to health professionals at a later stage in their

illness. Within the benefits system, a DS1500 report is a medical report used to fast track some Department for Work and Pensions benefits. It is issued by a health professional for those that have a progressive illness, as a result of which, it would not be unexpected for them to die within 6 months.

Prior to the pandemic, referrals from NHS partners and self-referring individuals into our benefits service comprised around 33% of clients who were eligible for a DS1500 report, so considered to be terminally ill. In the midst of the pandemic, for the second half of 2020, this rocketed to around 53%. If this data reflects numbers entering the healthcare system, it suggests that people in this period presented to health services at a later stage of their illness, or that illnesses were more progressed by the time diagnoses were reached, as a result of internal delays within the health system, and likely the picture is a combination of both elements.

Whilst the percentage of DS1500 patients decreases again in the third period, it is still notably higher than in period 1 (pre=pandemic), suggestive that more of these patients are later stage than would be in 'normal' times. This again is likely due to later presentation to the healthcare setting, and potentially a slower diagnosis *within* the healthcare setting. Full staging data is not yet available for these periods.

Date Range	% of clients eligible for DS1500 report
Pre-pandemic 1 st Sept 2019- 28 th Feb 2020	33.42%
Mid-pandemic 1 st July 2020- 31 st Dec 2020)	53.13%
Current time 1 st June 2021- 30 th November 2021	40.40%

The Government “Stay Home and Save Lives” message was taken very seriously, and people didn’t want to trouble their GP. The UK study ([Cancer symptom experience and help-seeking behaviour during the COVID-19 pandemic in the UK: a cross-sectional population survey | BMJ Open](#)) showed that of the participants who experienced a cancer symptom during the pandemic, 44.8% had not contacted their GP, with not wanting to waste a doctors time, make a fuss or put a strain on healthcare services being cited as frequent reasons.

Case Studies

1. Mrs McDonald was referred to us from a lung cancer clinic in July 2021. She had been diagnosed with a very advanced lung cancer which was stage 4 at the point of diagnosis. She had been initially dealt with on a Covid ward in March 2021 before subsequently testing negative for Covid. Investigations for lung cancer then commenced and her lung cancer diagnosis came shortly after. This was a total of 3 months after she was mistakenly treated for Covid. Mrs McDonald sadly passed away in September 2021.

Unfortunately, in instances where we are supporting a client with such a limited prognosis, any welfare benefit support we help them obtain is only useful for a limited period. On this occasion, our advisor could support the client and his partner to claim a fast-tracked non-means tested disability benefit, a disabled parking badge to assist with getting her to and from hospital appointments, and to set up a claim to support both Mrs MacDonald and her husband, for Universal Credit to support with living costs and housing costs.

2. Mr Simmons was diagnosed with bowel cancer in February 2020; he was due to have surgery in March 2020 but due to pandemic this was cancelled.

He frequently contacted his local hospital to see when he would have the surgery but was told to await contact from the hospital. This was ongoing, with Mr Simmons repeatedly requesting updates until September 2020 when he finally had the surgery. During this time he was extremely anxious and stressed worrying that the cancer would spread. Unfortunately due to the delay he required follow up treatment which wasn't initially needed so had to endure 6 further months of chemotherapy. This resulted in a longer recovery period which meant he was off work for over 12 months in total. Mr Simmons understands that the COVID-19 pandemic and its effects impacted his treatment, however feels very let down that no one kept in contact to reassure him he would be seen and treated and is now constantly worried the cancer will return due to the delay in treatment.

During the period that Mr Simmons was waiting for surgery, our advisor assisted with obtaining a grant payment to help him with the escalating costs of taxis as his pain levels increased and he became unable to drive. Due to the delay in surgery he faced an increased amount of time off work than was originally anticipated. Subsequently, his sick pay came to an end but he remained unable to work. Our advisor applied for a contribution-based income replacement benefit to support him through this time. Due to the effects of her surgery and follow up treatment that was required, Mr Simmons also qualified for a non-means tested disability benefit which our advisor assisted with from the application stage through to the benefit being in payment.

Mobile Units

Our four mobile units have continued to deliver services throughout the Covid 19 pandemic providing much needed clinical space to deliver services where they are needed. We have offered this facility throughout the pandemic to support a variety of services where they have been negatively impacted by the pressures on the NHS.

We have used the units to support numerous partners/services including

- Providing Covid vaccinations for hard to reach groups
- Screening programmes such as Aortic Aneurysm Screening
- Enabling Head and Neck patients to be seen outside the hospital with less risk of infection
- Lymphoedema and Cellulitis Services across Wales
- Providing increased capacity in BCUHB over Christmas 2020/21
- Ongoing cancer treatment clinics
- Clinical trials
- Hospice services

We have had conversations with many other partners about potential use

- Supporting a Haematology service with phlebotomy
- Providing a partially funded staffed solution for treatment delivery in partnership with Health Boards
- Newborn hearing testing/Diabetic retinopathy screening programmes
- Extra capacity outside Emergency units

Emotional Support

During the early days of the Covid 19 pandemic it became increasingly clear from feedback from our clients/patients that the negative impact on mental health and wellbeing was significant. We sought funding to create a Cancer Support Specialist role to provide both practical and emotional support to those with terminal diagnosis. This role was active between March and September 2021. This role incorporated providing support with any concerns around practical matters such as funeral planning, insurance, wills, digital footprint etc as well as support for the individual and family members/carers for the emotional impact of this diagnosis.

Examples of feedback from clients during the pandemic include

- lack of response from leaving messages with CNS teams,
- not having the time to speak with nursing teams to have their questions answered,
- very little emotional support, leaving people struggling psychologically
- the trauma of not being able to be with a loved one during appointments and treatment and even pre or post death.

Some of the Cancer Support Specialist role was to liaise with nursing teams to request they contact the patient or family due to little contact or support.

Our new Counselling service will focus on the emotional and psychological wellbeing of the patient and loved ones – through both individual sessions and group work.

Case Study

1. Telephone call to a DS1500 patient and spoke with patient's daughter and granddaughter regarding End of life (EOL) conversations and wishes. They had received very little support and didn't have any awareness of what "Palliative" meant or who to turn to for help, guidance, information or emotional support. They were assisted with emotional support, listening, advising, signposting and with internal and external referrals being made for further, more specialist advice. They were referred to our Nurse led support line for EOL advice and difficult conversations such as Advance Care Planning (ACP), and Do Not Resuscitate (DNR), they were also supported by our benefits team for help assessing benefit entitlements and future advice with help with funeral costs etc. Follow up calls were made to provide them with emotional support and they felt able to ask how to approach the patient's wishes, what to do, what to ask, what will need doing from a practical level. Bereavement support continued after the patient died and they were also signposted to bereavement services for further support.

Sing with Us

Our Sing with Us choirs have been supporting people affected by cancer for 11 years, by bringing people together to sing, make friends and support one another. Tenovus Cancer Care has researched the positive benefits of singing, and found that it not only improves mental health and wellbeing, but can also lower inflammation in the body and improve immunity.

Before the pandemic, our choirs met weekly to rehearse and also performed regularly in their communities. The lockdown restrictions of 2020 meant that we had to find ways new ways to work. Over the last 21 months, our choirs have transitioned to rehearsing online with Zoom choir rehearsals and virtual choir recordings as well as Facebook live sessions and YouTube videos. During the lockdown periods, we also increased activity virtually, with support such as emailing all choristers weekly, creating numerous WhatsApp groups, and engaging with choristers via private Facebook groups.

We are now finally (for now) back to face to face rehearsals and it's been powerful to see so many people in person again despite the challenges of singing in masks whilst also distanced from each other.

Quotes from choristers

1. I have felt your warmth & energy, not forgetting the love that you transmit during the virtual choir sessions. Your enthusiasm is infectious and you have helped maintain my sanity these last 7 months.
2. I honestly think you have saved me from utter despair during my most difficult year ever, you are all Super Stars!