

Caring about cancer in Powys

Issue 1
• Spring 2022

The official newsletter of the Improving the Cancer Journey in Powys Programme



This issue:

A View from the Top -
Richard Pugh looks back
at 2021 and shares his
aspirations for the year
ahead

PAGE 02

Holistic Needs
Assessments - what are
they? Meet our delivery
partners

PAGE 03

Forum Focus - how the
views of people living with
cancer are shaping the
programme

PAGE 04

Theory and Action

PAGE 05

Top Tips for people living
with cancer by people
living with cancer

PAGE 06

Ry helps promote the Books About Cancer project - see page 4

To read this newsletter
in Welsh please go to
Page 1

I ddarllen y cylchlythyr
hwn yn Cymraeg, ewch i
dudalen 1.

Improving the Cancer Journey in Powys programme



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Addysgu Powys
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THE VIEW FROM THE TOP

Richard Pugh is the Head of Macmillan Partnerships (Wales and South West) and one of the sponsors of the programme. Here he explains how and why Macmillan funded the ICJ programme and shares his aspirations for the future as we begin 2022.



"My aim is that we continue to raise awareness of the programme and ensure we offer every person diagnosed and living with cancer the opportunity to have a supportive conversation with someone who will listen and be able to do whatever it takes to support their needs."

IN POWYS each year a thousand residents are diagnosed with cancer and with no district general hospital have to travel out of county for treatment. The rurality and sheer size of Powys creates a unique and challenging environment for both patients and the services which offer support. That's why in November 2019, Macmillan joined forces with Powys Teaching Health Board and Powys County Council to fund the Improving the Cancer Journey in Powys programme and where I took up the mantle of sponsor, overseeing and helping to steer the programme in the right direction.

September 2020 summed up my frustrations and although we still face uncertain times, there has been a tremendous effort by the team to date to:

- better understand and capture the lived experiences of people living with cancer in Powys
- make connections with primary and secondary care providers (hospitals and local health care professionals like GPs) to understand how they support cancer patients
- bring in local third sector partners who are now trained and offering HNAs to people living with cancer.
- produce our first end of year report and complete our Theory of Change work which sums up our key achievements to date and sets out our stall for the next phase.

Next Steps

For me, the insights and involvement from people living with cancer form the cornerstone of the programme and help us to stay focused and grounded on what we are trying to achieve and how to do so. Our aim now is to increase our referral routes and continue to raise awareness of the programme ensuring that more healthcare professionals across all disciplines understand and know how to refer Powys residents in for an eHNA so that they can access support and advice that improves their quality of life.

What is the ICJ programme about?

The key aim is to ensure anyone diagnosed with cancer is offered Macmillan's **Holistic Needs Assessment (HNA)** shortly after their diagnosis. This tool allows the person to consider and get support to address any worries or concerns they may have whether these are emotional, practical, physical, social or spiritual. Over the past two years Covid has created numerous challenges for people living with cancer with people sitting on their symptoms and being afraid or not wanting to bother their GP during the pandemic. This has led to delayed diagnoses and treatment for many. My "you can't furlough cancer" comment made at the programme relaunch in



Welcome to our first newsletter

By Meinir Morgan - ICJ Programme Lead

Welcome to 2022 and our first Improving the Cancer Journey in Powys programme newsletter. So much has happened in the first formative phase of the programme that we felt it was time to create a newsletter to keep you up to date and also to review and recap on some of our key achievements so far. And who better to start us off than Richard Pugh. Our aim is to produce this newsletter twice a year so the next one will be due out in the Autumn. I hope you enjoy the read.

Meinir



What the professionals say?

As part of the programme two GPs - Dr Ruth Corbally and Dr Mel Plant were asked to explain why and how Powys residents could benefit from a eHNA or a HNA.

You can see their interviews via our

YouTube channel here: https://www.youtube.com/channel/UCpleAQcX8ow4jdt27GQ_iQA/videos



There are also videos from Powys residents who have shared their cancer journey experiences with us.

Meet our delivery partners



Bwrdd Iechyd Addysgu Powys
Powys Teaching Health Board



During the first part of the programme we've learnt a lot about the experiences of Powys residents who are living with cancer.

Alongside getting a better understanding of some of the key issues that people face following a diagnosis, our over-riding aim is that everyone living with cancer has the offer of a Holistic Needs Assessment (HNA). The offer could be made by someone like a CNS (Clinical Nurse Specialist) within the hospital trust where a person is receiving treatment OR if it's more convenient and timely, back at home, with one of our delivery partners. They are:

- The Bracken Trust
- CREDU - formerly Powys Carers
- Community Connector service which is run by PAVO - Powys Association of Voluntary Services
- Powys Teaching Health Board's Specialist Palliative Care Team

The HNA tool was developed by Macmillan several years ago and was originally a paper checklist that people filled in with a Macmillan nurse. Now the assessment can be completed electronically. Called the eHNA it can be emailed and completed by a person at home and at a time to suit them. They can complete the simple concerns checklist either in discussion with family members or by themselves. Concerns that a person might tick fall into six categories:

- physical issues like struggling to sleep, feeling fatigued or wound care
- practical concerns like work, money, household tasks or smoking cessation
- emotional worries including anger, sadness or feeling alone
- family or relationships concerns including sharing news or caring responsibilities for loved ones
- information and support concerns around diet and nutrition, exercise, making a will
- spiritual concerns around faith, beliefs and purpose in life

Once completed a trained link worker is then on hand to discuss the concerns and provide guidance, advice and information to the person so that their needs are addressed. The online option allows the person to log into their account and access Macmillan information sheets and their final Care Plan which might set out tips, contact numbers for other services like counselling or local support groups.



Residents with poor broadband connectivity can now borrow an iPad from their local library to complete the online form.

What we mean by...

People living with cancer

This term means people with a cancer diagnosis, their unpaid carers, their families and those important to them. It also includes people who have been referred to a hospital with a possible cancer diagnosis.



a Holistic Needs Assessment?

A Holistic Needs Assessment allows a person diagnosed with cancer to consider their key concerns via an easy to complete checklist. It's available in paper form or via an online link.

Once completed a trained link worker chats through said concerns and creates a plan to ensure the person gets the support they want and need.

Primary / Secondary Care

Primary care is the care provided locally by your GP, your dentist and via the local hospitals which serve Powys and are based in the county.

Secondary care is the care provided at hospitals outside the county like Hereford, Bronglais, Shrewsbury & Telford or Cardiff.

To get a Holistic Needs Assessment contact PAVO on 01597 828649, the Bracken Trust on 01597 823646 or if you are a carer call CREDU on 01597 823800.

Patients needing specialist palliative care tend to be referred directly from their consultant but please see page 5 for more details about the team.



Margaret is one of forum members

FORUM FOCUS

The Journeying Together Forum was set up a few days after the re-launch of the programme in September 2020. Forum members help to ensure that the programme listens to the views of people living with cancer. Meetings take place bi-monthly and forum members contribute to help shape the programme and increase our understanding on the things that impact their well-being.

The forum also co-produce and give their views on draft communication materials. They offer ideas about how best to raise awareness of the programme so that Powys residents know how and where to go to access a holistic needs assessment. Several health care professionals having spoken or attended the forum to provide information or answer questions including our clinical GP lead Dr Ruth Corbally, Richard Pugh and Sarah Wheeler who runs a project called My Life My Wishes which helps people to plan ahead when receiving a diagnosis. Two forum members also attend the Strategic Programme Board to ensure that the voice of the person living with cancer is heard in that setting.

Forum achievements

- Road tested the electronic version of the holistic needs assessment and gave feedback before the pilots were launched
- Shared their views around improving communication and relationships which resulted in a co-produced letter for GP surgeries to adopt and send to their patients
- Attended a workshop to feed in their views on what cancer services should look like going forward. (see page 5 for more details)
- Contributed their own stories which are included in a compendium on the ICJ webpage

Options to get your voice heard

If you are living with cancer and would like to get your voice heard the programme offers various ways for you to do so. You can:

- Join the forum
- Share your story so we continue to learn more about how and what support you receive when living in Powys
- Provide insights around specific key themes
- Provide feedback following a holistic needs assessment

Professionals are welcome to join a forum to share how they can support people . To find out more contact Sue on 01597 826043 or email ICJPowys@powys.gov.uk

INVOLVING YOU FROM THE GET GO



Tim and Ry (pictured above) both spoke at the ICJ launch about their respective experiences of living with cancer. Ry as a carer and Tim as someone living with cancer. Both have continued to contribute their views and insights and agreed to become the faces of our "Books about Cancer" project. Thanks to a grant from Powys Teaching Health Board's Charitable Funds, Powys residents can now borrow a range of Macmillan recommended books from our libraries. The link below takes you to information about searching the library catalogue. When you click on the search function you can type in the word "cancer" or scroll down the first column on the left. Towards the bottom of the page you'll see the Books About Cancer link. If you prefer pop in your local branch to request a leaflet or ask more about the books on offer. <https://en.powys.gov.uk/article/1306/Search-the-library-catalogue>

News in Brief

Summer Events Planned

Plans are underway to set up three ICJ Information Days during early Summer to raise awareness of the programme and offer people living with cancer a chance to find out more about how we are working to support them following a diagnosis. Healthcare professionals and all partners will be invited to set up stall at the events and share how their services can help. Keep an eye out in the local press and on social media for more details.

Money Advice

If you are living with or supporting someone with cancer there may be benefits and support (e.g. blue badge) that can be accessed via the council's Money Advice team. They receive some funding from Macmillan and can advise.

Get in touch by visiting: <https://en.powys.gov.uk/moneyadvice> and fill out the request form.

Farewell from Jeremy

Jeremy Tuck, the Assistant Medical Director who led the programme from Powys Teaching Health Board's perspective left his post at the end of January. In his farewell message he said:

"I would like to congratulate the programme team for moving the ICJ forward and thank all our other partners for the success that has so far been achieved. I know the ICJ programme will be a success because it is the right thing to do. We all want to see an improved cancer journey rolled out for the people of Powys."

Theory into practice

Last summer, three virtual workshop sessions took place so that all stakeholders could step back and consider what progress had been made and explore what the potential long term outcomes and objectives were going forward.

Called a *Theory of Change*, attendees included health care professionals, delivery partners and people living with cancer.

All were asked to consider what success could look like in ten years' time and how people living with cancer in Powys would be better supported if the programme had delivered.

All the feedback was analysed and a comprehensive report produced by Bright Purpose (specialists in the field) which clearly outlines the ambition and next steps for the ICJ in Powys programme.

The Theory of Change report is available at:

<https://www.powysrpb.org/icjpowys>

"The exercises gave all parties an opportunity to really reflect on the work achieved to date, consider what success could and should look like and then contribute their thoughts and ideas. As a result we have an ambitious programme for change which moves the theory into positive practices for people living with cancer in Powys."

Meinir Morgan, ICJ Programme Lead.

Introducing our two Macmillan cancer leads



Dr Ruth Corbally is the Macmillan GP Cancer Lead and the Clinical Lead for Cancer for Powys Teaching Health Board.

Dr Ruth has been instrumental in supporting GP practices in Powys to utilise Macmillan's Cancer Quality Toolkit and sign up to on-line training modules. These aim to raise awareness of cancer and help practice staff to better support patients who either have suspected cancer concerns or need a care review following treatment.

Launched in May 2019, 131 practices across Wales registered an interest (31%) in the toolkit with nine practices (56%) doing so in Powys. Four have now completed the toolkit. Dr Ruth's team also consists of two other GPs who support patients with a terminal diagnosis. Dr Mel Plant and Dr Antonia Bradley. All GPs in Powys receive a regular newsletter which provides cancer updates including ICJ programme news.

Louise Hymers is the Macmillan Lead Nurse for Cancer and Palliative Care in Powys.



Louise is responsible for ensuring both cancer and palliative care are patient centred. She manages the Specialist Palliative Care Team based in Powys Teaching Health Board which provides palliative (symptom and end of life) care expertise to people with advanced and progressive conditions including cancer. The team support people within their own home and through outpatients in local Powys community hospitals. They work closely with primary care colleagues, hospices and the specialist palliative care teams in secondary care (hospitals outside Powys). The team also support people to consider and plan for their future via a project called "My Life My Wishes" <https://pthb.nhs.wales/about-us/programmes/my-life-my-wishes/>

IMPROVING THE CANCER JOURNEY IN POWYS PROGRAMME

Top 10 Tips for people living with cancer by people living with cancer



Macmillan Cancer Support, Powys County Council and Powys Teaching Health Board are working together on a three year funded programme called Improving the Cancer Journey (ICJ Powys) in Powys to improve the support given to Powys residents locally following a cancer diagnosis. We've been speaking to people living with cancer (PLWC) about their experiences. They've shared their stories and offered some tips and advice to others about what worked for them when going through a cancer journey. They are...

1) Take someone with you to all appointments



Medical staff provide lots of information but it's hard to remember everything by yourself. If allowed it can be really good to have someone you trust by your side who can listen too.

2) Ask for a copy of paperwork



Having a copy of any letters or documents that give information about a diagnosis, prognosis or treatment is really useful so you can re-read but also share with others including your GP.

3) Keep a journal



This can help you to jot down how you are feeling, what your consultant said and can be useful to refer back to ahead of future appointments or to share with family members. OR keep an A4 summary sheet of the major facts, dates, previous meds, treatments & results if a journal isn't for you.

4) Take a list of questions



It can help to jot down questions as they arise in between appointments - maybe in your journal or a notepad - so when you sit in front of the consultant you don't go blank or forget what you wanted to ask.

5) Take your own notes if alone

If you are on your own visiting a consultant, don't be afraid to get out a pen and pad and take your own notes and ask the consultant to repeat things or explain them in plain language so you understand what's happening.

6) Record your consultation



Some consultants are happy for you to record your session on your mobile phone so you don't forget important facts and can share this with family. This can be useful if Covid restrictions mean you have to go it alone. Please do seek permission first though.

7) Set up a family What's App group

For family members it can be useful to share key information amongst themselves which the person living with cancer (PLWC) doesn't necessarily need or want to see.

This can be really helpful in saving the PLWC having to repeat themselves several times over to family/friends.



8) Feel informed

The language used by all involved in your care can be confusing and it's hard to say "I don't understand what you mean." If you feel unsure about anything to do with your diagnosis, prognosis or treatment plan just ask until you feel informed and clear.

9) Get a HNA

Following a cancer diagnosis a holistic needs allows a person diagnosed with cancer to consider their key concerns via an easy to complete checklist. Once completed a trained link worker chats through concerns and creates a plan to ensure the person gets the support they want and need. **CALL US**



For more information about the ICJ Powys programme or how to get a HNA (holistic needs assessment) you can email, call or visit our webpage :



ICJPowys@powys.gov.uk



call 01597 826043 Mon-Fri



visit our webpage by scanning the QR code below or go to:
<https://www.powysrpb.org/icjpowys>

10) Talk to someone



The Macmillan Support Line offers free, confidential support to people living with cancer and their loved ones. If you need to talk, we'll listen.

Call 0808 808 0000 7 days a week
8am - 8pm

OR you can visit the website to chat online or get more information.

<https://www.macmillan.org.uk/>



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