Improving the Cancer Journey in Powys programme.

A compendium of stories from people living with cancer in Powys.

Summer 2020 - Summer 2021

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Over the past 12 months we have listened to the experiences of over 40 Powys residents - some living with cancer and others who had cared for loved ones. Here we share their stories - some use a pseudonym or initial to protect their identity. The insights given will help us improve our understanding of what support people are offered, want, and need, following a diagnosis of cancer. These stories play a key part in informing the Improving the Cancer Journey in Powys programme.

LISTENING TO PATIENT STORIES
KEY THEMES

1. Pre-diagnosis, diagnosis and prognosis
2. Co-ordination of Care
3. Emotional Support & Care
4. Patient Voice and Choice
5. Carers Rights and Voice
6. Practical Support offered in the county
7. Relationships and communication
8. Transport and Travel
9. Education and Information
10. Advance Care Planning

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MACMILLAN CANCER SUPPORT

Ten key themes were identified through the 40+ conversations that took place with people living with cancer.

The stories that follow provide valuable insights into each and every person's cancer journey. They show how different each journey can be whilst highlighting how the same themes surface in the conversations held. Whether the topic is about the relationship with GPs and consultants, travel and transport, or how as a carer, a cancer diagnosis for a loved one affects your own mental health, they are all important in better understanding Powys residents' needs.

By listening to peoples' stories, we aim to put in place a model of care that improves the cancer journey for anyone living in Powys who receives a diagnosis of cancer.

1 - Emotional well-being was a strong theme that came out from conversations.

The aim of the Improving the Cancer Journey in Powys programme is to ensure that everyone affected by cancer is able to live life as fully as they can, by providing practical, physical, emotional, spiritual and social support so people can achieve what matters most to them.

CANCER
YOUR JOURNEYS

1. **Martin's Story - Prostrate Cancer**
2. **Becky's Story - Breast Cancer**
3. **Alan's Story - Bladder Cancer**
4. **Louise's Story - Breast Cancer**
5. **Margaret's Story - Secondary Breast Cancer**
6. **N's Story - Kidney Cancer**
7. **Karen's Story - Breast and Ovarian Cancer**
8. **Tim's Story - Lymphoma**
9. **J's Story - Breast Cancer** *(How Times Change)*
10. **Mary's Story - Skin Cancer**

11. **Tina's Story - Cancer of the Oesophagus**

Martin's Story

Martin who lives in the south of the county was 55 years of age when he was diagnosed with prostate cancer. His father and a friend of his father's had both been diagnosed and he knew that he had a 1 in 3 chance of also having it. This led him to request a prostrate-specific antigen (PSA) test from his GP when he noticed a few changes.

Martin's first test came back below 3 which his GP was not overly concerned about. He remembers being told that it was only when it goes above 3 that he'd need further tests and an examination via a urologist.

PSA Test Request

Because of his family history Martin made sure he had a test every two years and because of subtle changes he’d noticed (getting up more to go to the toilet in the night and taking slightly longer to go), he decided to ring his GP practice and ended up speaking to the Senior Partner and explained what had been happening. She decided to refer him to a Urology specialist. He had a rectal examination and more tests and this time his PSA test was 3.2. He also had a magnetic resonance imaging (MRI) scan which would normally have meant up to a 3 month wait, but he ended up having this within a fortnight at Hereford hospital. He was told that the multi-disciplinary team had checked his results and he had a small lesion and they needed to do a biopsy. This was carried out at the Nuffield private hospital in Hereford in April 2020.

2 - Martin continued to run throughout his cancer journey.

Because of lockdown Martin had a conference call about his results with his consultant. A specialist Macmillan urology nurse stayed on the line with him afterwards to talk through his options for treatment. She explained that he had two choices - an operation or radiotherapy. She told him to have a think about it for a week and someone would be in touch. She said some leaflets explaining the options would be posted out to him. However, these didn't arrive so Martin chased them up and had them emailed to him instead. Martin remembered thinking that an email would've been the easiest option so he could have had the information more quickly.

Treatment Options and Choice

Martin was also told by a Macmillan Support Worker that he could fill in a form (HNA – holistic needs assessment) which was emailed to him and he could discuss it and his needs. The form arrived and he filled it in and discussed it with the support worker. As a result he realised he did not need much support at that time. He did his own research and decided that he wanted to have radiotherapy not the operation.

The Consultant tried to persuade him otherwise saying the operation was quicker and would remove the cancer but because Martin is a full-time carer for his wife, he decided he didn't want to leave his wife or go into hospital because of Covid and the potential risks that could ensue.

He said he felt that he was fit and able and although Macmillan was really supportive and offered to provide respite care for his wife so he could have the operation, it was his choice. Martin mentioned that the radiotherapy treatment schedule that he was offered had actually worked out well for him and meant he could continue to care for his wife for most of the day and also fit in a visit to his father in Merthyr on route to the hospital. He was glad he didn't have to ask to change this and his daughter was luckily able to homework due to Covid, so whilst he was getting treatment she was at home and able to help her mum.

Radiotherapy

Martin said his radiotherapy treatment took seconds but having to arrive at the hospital with a full bladder was sometimes a little bit tricky! He said there were lots of men sat in the waiting room who were in need! He said that it took about 3 minutes for the nurse/consultant to get you into the right position for the radiotherapy and then you are zapped for about 30 seconds. You have to go every day for 20 sessions. He sympathised with any man who hadn't got their own means of transport and was reliant on hospital or community transport to get them to their appointment. For himself, he'd praised the hospital as he'd been provided with a parking pass based on his condition which had been a big help.

Observations

His observations around his cancer journey to date were that overall, the co-ordination of care was good bar a hiccup with a scan that he thought was at Cheltenham, and on arrival there, had been told it had been arranged at Hereford - right date, wrong hospital. He had no side effects from the radiotherapy and said the Macmillan nurses at the hospitals were really pro-active and friendly, chatting to those patients waiting to be seen. For him the next steps were being monitored for the next five years. He will have 3 PSA tests over the next six months. His Cheltenham consultant has told him to ring if anything changes and not to wait.

In terms of the HNA and his needs when back in Powys he said he didn't need anything. He is retired, has good family support networks and was financially secure. He didn't need to reach out for any other services but recognises that this may not be the case for everyone.

The Age Factor

He feels that once a man hits 45 years of age and in particular if there is a history of prostate cancer in the family, they should be offered a regular PSA test. He said that men can have an enlarged prostrate that isn't cancer, but they can be scared to seek treatment, but it's easily treated.

He said ***"Knowing my own body helped me to realise that things weren't quite right."***

Having been a police officer for 30 years he said that in that job he could have been too busy to notice his symptoms and he was sure the same could apply to other men. He'd like to encourage more men to get a PSA test and felt the Macmillan leaflets he'd been given explained prostate cancer really well.

The key themes from Martin's Story are:

- Pre-diagnosis, diagnosis and prognosis
- Co-ordination of Care
- Patient Voice and Choice
- Relationships and Communication
- Education and Information
- Carers Rights and Voice

Becky's Story

Becky was diagnosed with breast cancer in late 2020 at the age of 50. She is married with three children and when she shared her story was 11 days into her first round of chemotherapy.

"I received extremely prompt action from my GP surgery and the GP I first saw with my lump recognised that it was a genuine cause for concern and immediately dealt with me thoughtfully but very efficiently. I have been under the care of Wye Valley NHS Trust through Hereford County Hospital ever since and have received exemplary treatment and care. I have been handled with sensitivity and compassion throughout and have also been treated very promptly. All medical staff I have dealt with have been extremely confidence inspiring.

"From diagnosis on New Year's Eve 2020, I had my operation in mid-January and have been receiving chemotherapy since mid-February. There have been no delays whatsoever to my treatment in spite of the current difficult circumstances due to Covid-19. Because I have an underlying condition, I am also a patient of a consultant at Nevill Hall Hospital and there has been some need to coordinate treatment between these two hospitals operating under different NHS Trusts and in different counties. This has been managed by the consultants at the relevant hospitals without a hitch.

My Hair Dilemma

3 - Becky - *before her Brave the Shave fundraiser.*

"Before chemotherapy I had very long hair and when it became apparent that I was likely to lose all, or most, of it I asked my husband to cut it very short so that it would feel less shocking when it came to shaving it all off. I decided that it would be a shame to waste the fundraising opportunity presented by shaving my head and set up a Brave the Shave fundraiser through Macmillan. My husband and three grown-up sons all joined me and we shaved our heads together as soon as I started to notice I was getting bald patches. This solidarity made me feel amazingly supported and helped me psychologically with my new baldness – I did not feel alone! It also helped the rest of the family to feel more involved and so opened up channels of communication about my illness, which I feel is so important when dealing with cancer as it affects the whole household. To our surprise we raised a fantastic £2,543 for Macmillan against a target of £300 and we have donated my hair and that of our eldest son who also had long hair to The Little Princess Trust. It is good to know that something positive has come out of my cancer experience!"

Blood Tests at GP Surgery

"To date, the only issue I have come across as a result of living in Powys and having no local hospitals offering cancer services has been in getting my blood tested in a timely and convenient fashion. As it is a

two hour and twenty-minute round trip to Hereford Hospital, I was advised that my pre-chemo blood tests should be undertaken at my local surgery and sent to Hereford for processing on a specific date.

"However, although ringing two weeks in advance I was told that there were no blood test appointments left on the specific date I needed it to be taken. This meant I unfortunately had to travel to Hereford whilst experiencing the side effects of chemotherapy in order to have a blood test that took five minutes to administer. Not ideal! However, it proved to be a one-off as when I rang for a subsequent blood test at the surgery, I persevered with the receptionist and persuaded her to talk to the nurses for me. They agreed to squeeze me in once they understood my full circumstances so from now on, I will just be a little more forceful and explain everything very fully.

"It is now early Spring 2021, an uplifting time which is helping me to look forward to the future when my chemotherapy has finished and I can once again live life to the full. The experience of cancer has given me a different perspective on the future and emboldened me to go ahead and do the things I have always wanted to do. So, I am considering retraining once I recover to allow me to change careers from researcher to advocate for young people in care as I realise that this is something, I have always felt passionate about.

"Meanwhile, as I cope with my chemotherapy, I hope that the ICJ programme will be implemented as soon as possible as I believe that this type of holistic and personalised support will be enormously beneficial and would make myself and everyone else facing cancer feel nurtured and listened to and so less afraid of the path ahead."

4 - Becky decided to donate her hair and "braved the shave" along with her husband and three sons and between them they raised over £2500 for Macmillan Cancer Support.

The key themes from Becky's story are:

- Pre-diagnosis, diagnosis and prognosis
- Co-ordination of care
- Relationships and communication
- Education and Information
- Patient voice and choice

Alan's story

Alan was diagnosed with bladder cancer in 2017 at the age of 64 and then again in late 2019. He was first alerted and concerned when he passed some blood and immediately got in touch with Shropdoc because it was the August Bank Holiday and no scope to see or contact his GP.

He was told to get himself down to Ludlow Hospital. The doctors thought it could be polyps and a letter was sent to his GP and then the GP referred him for tests. He was sent to Hereford for tests within a week and was subsequently diagnosed with bladder cancer at the beginning of September. Somehow, and unfortunately, his medical record and details were misplaced and he ended up having to wait for his operation. This took place in the last week in October 2017 and he was then sent home being told he needed a check-up every three months initially. This would then move to six monthly check- ups.

“Getting a diagnosis of cancer really knocks you about.”

Alan felt really low and depressed and spoke to his GP. She referred him to seeing a Macmillan nurse who attended his local surgery at the time. He was able to talk to her about how he was feeling, and she suggested he get in touch with the Bracken Trust. He rang them that afternoon and made an appointment and has subsequently received both counselling and massage treatments to help with his recovery. Alan felt the counselling was excellent and in his words ***“sorted me out.”***

At one of the Bracken Trust drop-in sessions held at the community centre in Knighton, Alan met an officer from the council's Welfare Benefits Team who was on hand to chat to patients about financial support. She helped him to get a blue badge for which he is grateful. However, on Christmas Eve in 2019, he went back for his six monthly check up and his consultant found that the cancer had come back. What a lovely Christmas present! In January, 2020, he had a follow up operation to remove the tumour.

His consultant said, ***"We caught it right as it was very small."*** Another check-up followed in April/May 2020. Subsequently his check up in November 2020 gave him good news - all clear, but he did have to pester for his check-up to happen because of Covid. He knew that a lot of cancer treatment had been stopped for six months due to Covid so was a little worried about when his check-up would take place. More recently, Alan has unfortunately been told that the cancer has come back and is in his bladder. He's just started four rounds of chemotherapy. One round equals six weeks of treatment one day a week and then a break and then another round. He says he's fortunate that he's not feeling any side effects currently and is continuing to work in between his treatment driving other people to their hospital appointments.

Alan is very clear about the impact cancer has had on him. He says: ***"Your whole outlook on life changes as a result of a cancer diagnosis. My attitude has changed, and people ask me why I'm always joyful, but I am, because I'm here."***

Alan and his wife found it all a challenge and both needed someone to talk to. They both attended a course at The Bracken Trust, in March 2018 and found that it was helpful for them both. This highlights the pressures that all family members face when supporting the person with the diagnosis. It impacts the wider family as well as the person receiving treatment.

Employment and Cancer

Alan used to work for a quarry near Knighton. He worked long hours and was due to retire when he was first diagnosed. His employer was really supportive and kept his job open for him. He ended up going back to work for them but had to cut his hours and finally due to getting easily tired he decided it was time to retire. He's glad he did as he feels more relaxed and although he does still get tried, he knows his limits.

He now acts as a volunteer for the Bracken Trust and is also a Community Support driver in Knighton. At the time of the conversation he was missing the links to the trust and looking forward to picking up his duties when they reopen. He was still driving patients to the hospital and in January 2021 drove over 1000 miles. The Community Support team always allocate him to drive people going for cancer tests because of his cheerful outlook. He says he chats to them and shares his story with them telling them that although they are nervous, he'll be there to take them home again. He's sure that sharing his story helps them to feel calmer and able to face their appointment knowing they are not alone. He says the two questions that pop into your head when you get told you've got cancer or think you have are ***"How long have I got?"*** and ***"Why me?"***

5 - The impact of cancer - the good, the bad and the ugly.

When asked what the good, the bad and the ugly was about his cancer journey he said for him....

- *The Good was and still is the Bracken Trust.*
- *The Bad was the lack of support or information following his first diagnosis where he felt anxious and depressed and left to it.*
- *The Ugly, of course, was the cancer in the first place, and the impact getting a diagnosis has on your mental health and family.*

The key themes from Alan's story are:

- Emotional Support & Care
- Co-ordination of Care
- Practical support offered in the county
- Relationships and communication
- Transport and Travel

Louise's Story

Louise was diagnosed with breast cancer, duct-carcinoma in-situ (DCIS) in 2015, and, in 2020, was pleased and relieved to hear that she had been clear of cancer for five years. At the time she found her lump she had a very good friend who had had breast cancer and their circle of friends were still reeling from this.

6 - Louise has been clear for over five years now.

She says her friend's experience had raised her awareness of breast cancer and she'd checked her breasts more consciously as a result. In Mid-March 2015, she found a small lump underneath her right breast on the day before Mother’s day. Her recollection at this point was ***“I remember breaking into a cold sweat, I think I knew.”***

She rang her friend who told her to get it checked and two days later she saw her GP who examined her. She left the surgery with her husband who tried to reassure her, but she wasn’t feeling that relieved. Later that week, she found what felt like ‘satsuma seeds’ on her breast (which she now knows is pre-cancerous calcification) and went back to the GP surgery. She saw a different GP at the same surgery and was told she was already on the urgent referral list (she was shown the letter that the first GP had sent). She didn’t know a letter had been sent and realised that the first doctor had not wanted to scare her by saying anything.

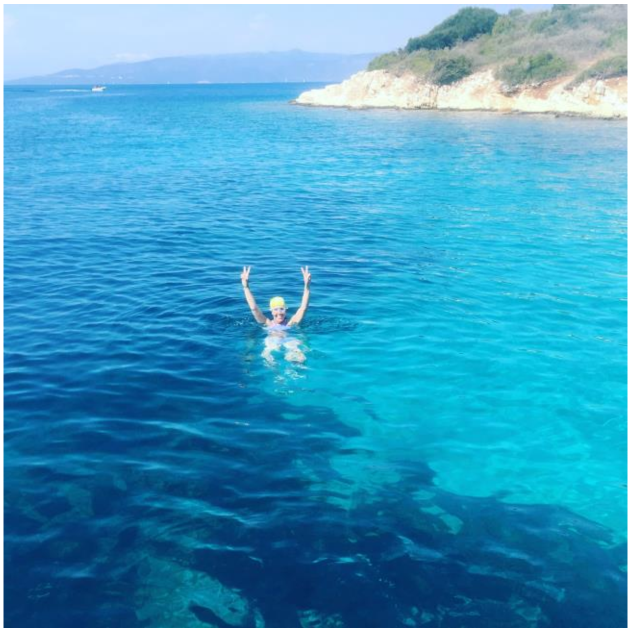
Louise was then referred to the Breast Clinic at Royal Gwent in Newport which was a one stop shop at that time. Because there were lots of public holidays at that time she had a wait a little while for her appointment. She remembers someone drawing on her breast and she thought, ***“Why are they drawing all over me?”*** She then went straight in to see the radiologist. Louise remembers feeling like she had gone from being a perfectly healthy individual with everything going for her to suddenly being in a room where someone said, ***“We need to check how far the disease has spread.”*** This was how the news was broken to her. It was particularly awful because her mother was in the room and she hadn’t told anyone apart from her good friend and her husband.

Within minutes of being with the radiologist, they started scanning her and they started speaking of disease. Louise was saying, ***“If it’s cancer, just say cancer."*** She remembers her mother being on other side of the curtain and being very aware that she could hear what was being said. She then had several biopsies that day. The consultant talked immediately about whether they would remove part of her breast or all of it. Louise says she was lying there thinking ***“What? What are you saying to me?”*** She left with an appointment to come in and see a consultant about treatment and her treatment path. That appointment was a couple of weeks later because of the public holidays. Again, a tricky time waiting and not knowing.

Treatment options

The consultant felt it was best to remove the whole breast and explained how the reconstructive surgery worked and whether skin would be taken from Louise's back. Louise felt she was given options and details about what each scenario meant. She felt she was involved and just wanted the cancer gone as quickly as possible. She understood that it was in situ which was good news meaning it hadn’t spread anywhere else. She felt her consultant was the perfect person for her because he spoke to her like an adult. She appreciated that and can remember one nurse asking her how she felt and thinking ***“I just want someone to tell me what they’re going to do.”***

She feels lucky to have had the breast surgeon she did. He had a sense of humour and she needed that at the time. The mastectomy was organised very quickly after that. She was in hospital for 10 days in her own room which was good. Louise feels that the reconstructive surgery was amazing. She did have to lose her nipple which was upsetting for her even though she tried to feel positive that she hadn’t had to go through any of the trauma of losing her hair or her eyelashes as her friend had. She then had to wear a surgical bra and was in pain for some weeks. She subsequently had check-ups soon after her hospital discharge and felt that everything was very organised and her consultant was “an absolute superstar.” Because of Covid, she couldn't physically go in to see her consultant but he rang her to say goodbye.



7 - Louise completed a sponsored swim raising money which provided closure for her.

Reflections and Mental Health

Overall, thinking back, Louise says the one big hiccup was the process and the way in which she received her diagnosis of cancer.

Ultimately although the GP was probably trying to protect her, it would have helped her prepare for the hospital experience if she'd have known that a referral letter had been sent for a suspected breast cancer. It was a real shock to hear the news at her first hospital appointment.

In relation to the ICJ programme and having no offer of a Holistic Needs Assessment at that time, Louise feels that for her, it might have been useful to be able to talk to someone about the paranoia that comes with a cancer experience. She did feel the Breast Care clinic nurses were good, but she was worried that she was being neurotic and wasting someone's time if she had questions so didn't ring them. She says you do feel a bit alone – what helped massively were her personal circumstances – her good friend who had been through it too. She thinks it would be difficult for someone on their own, or without much of a support system.

Louise said a GP friend recently asked her if she had been given an exercise plan after her surgery but she hadn't. She wasn't offered the therapeutic treatments like her friend but felt there was no need. She was offered psychological support which she didn't take up because she didn't want the cancer to define her. She felt confident that if she had any issues she could speak to the breast care clinic in Neville Hall whose card she was given and which she has made use of this as she has had one or two scares.

She thinks your paranoia levels are set quite high after having had cancer and that your mental recovery only starts afterwards because up until that point you're so busy coping with the physical side of things and the damage limitation for those you want to protect around you.

The experience does separate you from everyone – you are on your own dealing with it. The people around you can't share it and Louise wouldn't want them to. Louise feels there is definitely something missing in terms of how to support those caring for the person receiving a diagnosis or treatment. It can be a difficult time for those trying their utmost to support their spouse. After her own experience of worrying about her mother overhearing what was being said, Louise tried to go to most appointments on her own. ***"You find your ways of coping. But how do they cope? I'm not sure."***

The key themes from Louise's story are:

- Pre-diagnosis, diagnosis and prognosis
- Emotional Support and Care
- Patient Voice and Choice
- Relationships and Communication
- Carers Rights and Voice

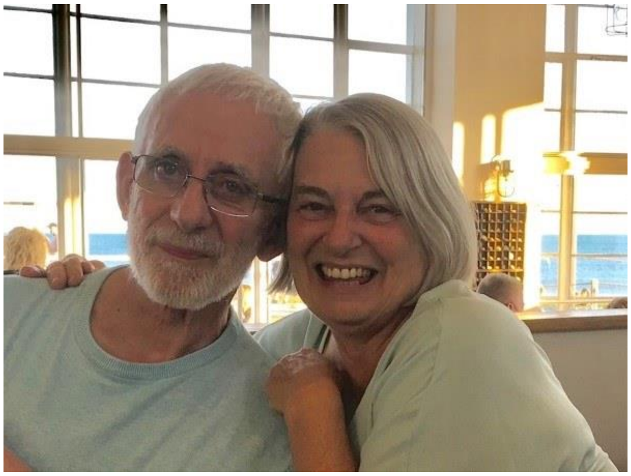
Margaret's Story

After an appointment with her GP, Margaret was originally diagnosed with breast cancer in Hereford hospital back in 2002 aged 54 but received a second diagnosis 14 years later.

Originally Margaret had surgery in Hereford for her breast cancer, followed by radiotherapy in Cheltenham. With the support of her husband's staff, they managed to wrap her treatment around her husband's work patterns which luckily involved him needing to travel in that direction. She remembers having to have radiotherapy Mon-Fri and being offered a room that she could stay in overnight. Care at Charles Renton Clinic was excellent with two Macmillan Nurses – one available by phone during her treatment plan. After this she took Tamoxifen for five years along with annual mammograms, which were clear. She was then signed off from the clinic, apart from attending the lymphedema clinic 2/3 times per year.

Secondary breast cancer

She was then diagnosed with secondary breast cancer in December 2016 and was shocked to be told she had 2- 3yrs to live. The cancer had spread to one of her lungs (right) and to her nodes under her collar bone. Her journey to diagnosis wasn't the best. She had a CT scan in October 2016 which finally led to her diagnosis after four visits to her GP between Jan- Aug 2016 with symptoms of coughing & getting breathless.



8 - Margaret and her husband celebrating their 50th wedding anniversary in 2018.

Margaret had read that people can visit GP 4-5 times before being sent for diagnosis so wondered whether there should any 'Red Flags' for GP's because of her previous breast cancer diagnosis. Eventually she saw a locum GP and was sent for tests- a biopsy and a CT scan between Sept – Nov 2016. Had these referrals not happened, she would have sought a private scan. *She said:* ***"What you want to know is what treatment do you or don't you need? There is a lot of anxiety about what they will do."***

Information and Resilience

Margaret attended a group in Cardiff for women diagnosed with secondary breast cancer and was surprised to find out that several of those attending had been diagnosed several years beforehand and were cancer 'survivors' of 10 + years. This gave her a boost and determination to prove people wrong about her prognosis. Margaret mentioned how everything was much more organised at Hereford with the primary cancer diagnosis in 2002, but not as organised for the secondary diagnosis in 2016. She had to chase for her outpatient appointments 2/3 times. Scans/blood results were not always available at the appointment times and appointments for the Hereford Clinic were generated from Cheltenham, but blood tests were centralised at Birmingham.

"Feels all a bit haphazard."

A chance discussion with a parent at a netball club where she coached (who also happened to be a GP) led to Margaret asking to be transferred to Velindre Cancer Centre instead which she did with an outreach clinic taking place at Merthyr. At the time Margaret said she remembers thinking: ***"I don't know anything about Velindre!"***

Pathways choice and travel

Margaret feels the ICJ in Powys programme is important but the pathways to treatment need to be clearer to have any impact or change the geographical pathways that people have to navigate. In Mid Wales for both primary and secondary breast cancer the treatment paths are so diverse and this can be confusing, stressful, and tricky for people having to travel to different destinations for different treatments. She feels it'd be helpful if GPs had to hand more information about your treatment centre options so you have a choice about where you could go. Two questions she'd like answered are:

- ***Why are Powys residents not given more information about options in Wales?***
- ***Where can you have chemotherapy or radiotherapy in Wales?***

This is particularly important for Powys residents because of the size of the county and the transport routes.

Because of a spread to her right lung, Margaret has been having daily oral chemotherapy and hormone combined treatment since April 2019. This combined treatment continued with three monthly cycles of scans and blood tests at an outreach clinic at Prince Charles Hospital at Merthyr Tydfil. If her results are OK she carries on with her treatment. This was working well until COVID 19 lockdown when under the first lockdown she was asked to drive to Velindre to have her blood test taken in the car park and then wait for the results and given the appropriate medication. For Margaret and her husband who was waiting for cataract surgery this wasn't possible so discussions ensued about how and whether her chemo tablets could be delivered to her home instead. All Margaret's other medication was delivered via the Powys Home Support service but as chemotherapy is toxic it was decided that these would have to be sent up via taxi from Cardiff. Subsequently Margaret now gets everything delivered by Lloyds Pharmacies.

Margaret has been a Netball volunteer for many years. At the age of 74, she has only recently given up coaching, for mainly Covid related reasons, and is thinking about writing a coaching handbook. She has some stories to tell about Netball and having cancer including the one about her chicken fillet!

Because she is quite resilient, she says it can also sometimes feel quite inhibiting to be able to say, ***"I'm feeling quite well thanks."*** to people who ask. Margaret sums up her cancer diagnosis by saying:

"Perhaps if we called it MBC (Metastatic Breast Cancer) it might be clearer and more helpful in terms of understanding? I have spoken with some people who think it's better than having primary breast cancer."

She believes people can live well with secondary breast cancer and hopes the ICJ in Powys programme will support people to do so.

The key themes from Margaret's story are:

- Co-ordination of Care
- Education and Information
- Relationships and Communication
- Transport and Travel
- Practical Support offered in the county

N's Story

N is 62 years of age and lives in east Powys. She first felt that something wasn't right back in early October 2020. N had noticed that she was nauseous and retching when her partner cooked certain foods. She was also losing weight. After some tests and a CT scan N was diagnosed with kidney cancer which had spread to her lungs. N was very shocked as she was someone who had always looked after her health. She enjoyed staying fit, cycling, walking, taking Zumba classes and eating healthily.

N feels that overall having received a diagnosis there was no other support and no one to talk to and that you have to be proactive and pester to get any help. Her GP suggested that N phone the Bracken Trust. She registered with them and got a counsellor.

"They are fantastic." she said.

After having tests, a multi-disciplinary team (MDT) discuss treatment options and N got a phone call from the renal consultant – a Mr A who said they could shrink the tumour or remove it and the kidney. N said the latter was her preferred option. He said: ***"Don't worry about the lungs we'll treat this with immunotherapy."*** N said her diagnosis was on 9 Nov 2020 and on 9 December her kidney and tumour were removed. She noted that this was quite fast really. The consultant was brilliant and filled N with hope. He told her that she was young and healthy and said ***"I'm going to do the best for you."*** He was very positive. After the operation, N spent five days in hospital. It was major surgery and as N had never been in hospital, she found it hard and was in a lot of pain. She was discharged and came home with no support whatsoever.

On that first day she managed to get into bed but couldn't get out the next day. She had no Occupational Therapy (OT) assessment at the hospital, no follow up care organised and no equipment. She had just been given a phone number for the ward. It was hell sitting on the toilet and she had a 10 inch wound to look after all by herself. Nothing was co-ordinated.

N rang the Bracken Trust, and they made a referral to the district nurses who came the next day. They said that they thought the hospital hadn't referred N because the wound was healing really well and they thought she would be able to manage it herself. ***"I found that really difficult and ended up finding a stool that I could use to get out of bed."*** Luckily, a friend who is an OT in Shrewsbury lent N a bed lever. N said she felt having some OT equipment would've made a world of difference. N has subsequently made a good recovery from the operation and was referred to the oncologist for treatment for the secondary tumours in her lungs.

Immunotherapy Treatment Trauma

Unfortunately, after having the immunotherapy treatment N got a high temperature, rang the helpline and was told to go to Cheltenham hospital. Her partner drove her there at 4am in the morning! It was the most awful drive – foggy and with flooding on the roads. Cheltenham use their Minor Injuries Unit out of hours and allowed her partner to stay until 8am in the morning with her when she was admitted. The hospital gave her a scan and thought she had an infection along the wound, so they gave her antibiotics. N was admitted on the Friday and they thought she could go home on the Monday but that didn't happen. N got terrible sickness and diarrhoea. She continued to get worse – had scans, X-rays, and antibiotics – they thought it was an infection still. Her temperature spiked at 40 degrees on the Thursday night and she had a ***"horrendous night lying by an open window lying in -7 degrees under a sheet shivering."*** The nurse was giving her intravenous paracetamol and saying they needed to be cruel and the window had to be open. The next day the temperature was managed but the next night it spiked again.

N said:

"I didn't think I'd survive the night or see my family again."

The consultant said to N that sometimes people come in for one thing but then things get worse. He tried to have a conversation to say if her heart stopped, they wouldn't resuscitate her because she had terminal cancer. She burst into tears and said *"I can't have this conversation now."* A lung specialist then came in and said he believed it was inflammation not infection. He recommended she come off the anti-biotics and that she was given steroids instead. These worked and her sickness went and her appetite came back. However, the downside of having the steroids was that they suppressed the immunotherapy which was aimed at reducing the tumours in her lung. N remembers the steroid dosage was 100mg a day initially. She said: ***"My friend is a vet and said that's the amount they would give to a horse!"***

Steroids and Sleep

N has subsequently been on steroids and says: *"The steroids are fantastic, but they make you hyper-active. I can't sleep. I've been reducing by 10mg every five days but I have to take sleeping pills."*

"I thought a lot about dying whilst I was there and I asked to see and saw a lovely psychologist – she came to see me twice and she was amazing and said there is room for hope – even though sometimes people won't say it. I still want to live, and I just don't know what the future holds. It's a big knock not being able to have immunotherapy."

N says the really dark times are at night. This is when you are in pain and need someone to ring for support. N has the chemo 24-hour helpline which is good. If N has a temperature or diarrhoea, she can phone or if she has problems with breathing at any point – although hearing that was scary. N says her main source of follow up support now alongside her GP, has been and continues to be the Bracken Trust and the counselling she receives. She has a session every fortnight with a counsellor - sometimes every week. One of the nurses then also calls her every week. And if she has a query or needs to speak to someone she rings and leaves a message and someone will ring her back.

Covid Impact on cancer journey

N does feel that Covid has affected the support that’s been offered to her. Because she is younger, she thinks that there’s an attitude that she can manage.

N has recently had her Covid jab by being on the reserve list and is awaiting her second jab. She said that although she's had her first jab, they won’t give it to her partner who is in his mid-50s which seems somewhat illogical. Her partner asked the GP if he could be prioritised due to her cancer but was told “no”. N feels she’s actually at greatest risk of catching Covid from him because he does the shopping, goes to the chemist etc.

Because of Covid, N started to use her iPhone to record her consultations with her oncologist as she had to go by herself and this way she can share the conversation with her partner and children which saves her having to go back through it all and remember everything too. A very handy tip for anyone else. Just to be clear N did ask the oncologist who gave permission for N to record their session.

Family and Friends

Family, friends and work colleagues have been amazing and helped N’s well-being. Everyone is rooting for N and she feels very loved and fortunate. N says she’s not well enough to work at the moment but she does miss work. It’s been part of her routine. In terms of her well-being, N goes for walks, is knitting everyone a hat and she enjoys reading. Recently N has also been spending time in the garden and is a keen gardener and is particularly pleased with her lupins.

9 - N's proud of her lupins which flowered beautifully this year.

Improving support within the county

N said: ***"In terms of Powys because it's so rural I felt very lonely, isolated and unsupported. I had to be proactive. I feel I would've have had better support in England. It feels like any support is external – like the Bracken Trust - who have been amazing although again they are only available 9am – 5pm, but overall, I feel there is no cohesiveness around any support that is available. Powys is mainly relying on charities to support people."***

N would really like there to be 24-hour support in Powys for people with cancer so there is always someone that people can ring for support and guidance. N believes it may need to be a partnership but there needs to be some point of contact because you are very isolated when you have cancer and live in a rural area and it can be very lonely.

It'd be good to have some cohesiveness between the services offered. It's very unwieldy and different residents get different services depending on who knows what and how proactive they are. Ahead of her next oncology appointment N is going to stay well, eat well whilst her appetite is back and hope that she'll get offered her immunotherapy treatment. If not, she may be prescribed tablets or look at private options. Her kidney consultant has said that the cancer is not in her bones or her liver but is in both lungs. Originally there were 10 or 11 tumours identified in November 2020. The Oncologist told N her cancer was aggressive hence the removal of kidney as best option followed by immunotherapy. But, as the latter hasn't worked, she's now left with cancer in her lungs. N added that evidently Kidney cancer doesn't respond to chemo or radiotherapy.

The key themes from N's story are:

- **Pre-diagnosis, diagnosis and prognosis**
- **Co-ordination of care**
- **Emotional support and care**
- **Patient voice and choice**
- **Practical support in the county**
- **Relationships and communication**
- **Advance Care Planning**

Karen's Story

Karen was firstly diagnosed with breast cancer in 2003 at the age of 41. She had an operation, chemotherapy and radiotherapy and was given Tamoxifen and told she needed to take this for five years. Then six years later in 2009, she was diagnosed with ovarian cancer and had to have chemotherapy once again but that wasn't the end of her journey.

In 2015, she had secondary breast cancer and following more chemotherapy ended up having a double mastectomy. Then four months later in the January of 2016, she had a recurrence of ovarian cancer which led to her having to have a Stoma bag fitted as the tumour was attached to her bowel and part of it had to be removed. She has the BRCA gene which means that the cancer runs in her family and can and does reoccur. She lost her sister 12 months ago and her best friend 18 months ago. Her niece also carried this gene and has had cancer and reconstructive surgery.

Conveyor Belt

Karen has lost her hair three times, has had radiotherapy and chemotherapy. She had to give up her job as a childminder last time around which she'd done for over 32 years. She now works at the local school doing playground duty and then spends her time doing various crafts like knitting, making jewellery, decorating slates and creating sweet bouquets too. She loves her craft work, and this helps her well-being. Karen says that having a diagnosis of cancer leads you onto a conveyor belt where you go from one appointment to the next not knowing what is round the corner. However, all the medical staff are amazing whilst you are being treated etc. But then you get told you don't need to be in hospital or see anyone anymore or for six months or so and you come home, and you are on your own.

But, you still worry about every little twinge or pain you get. You feel anxious and scared and very vulnerable. It completely changes your life, and you ask yourself – who am I? You lose your sense of self, of your identity and worry about the cancer returning. Karen felt isolated, left out on a limb, and very alone following her first operation and was quite depressed and anxious. She feels that she has, to a certain extent, lost her identity as a woman. Last time, she accessed counselling through Shrewsbury Hospital for six months to help her deal with the anxiety and this has been helpful.

Inspire Welshpool

Karen then found and attends the Inspire Welshpool group which has been a real lifeline in terms of being able to talk to other women who have cancer. Being involved in this helps people who are newly diagnosed to hear and get support and reassurance from those who have lived experience. Karen says this group has been invaluable in helping her to share her story and to build up friendships etc. Karen hopes the ICJ in Powys programme and whatever is put in place will help others to feel less alone following cancer treatment. And, that people can talk to someone and be listened to. Sharing your fears and having someone who listens to you is key.

The key themes from Karen's story are:

- Pre-diagnosis, diagnosis and prognosis
- Co-ordination of care
- Emotional Support and Care
- Relationships and Communication
- Practical support offered in the county

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Tim's Story

Tim was diagnosed with colon cancer and lymphoma in October 2016 and has had chemotherapy at The Lingen Davies Centre at the Royal Shrewsbury hospital since December 2016. By early 2021 he had received 90+ cycles with a cycle being a period of 14 days. There have been many rest and holiday periods in his 4+ years of treatment.

Originally when Tim was diagnosed with bowel cancer, he was told it was terminal and he had a Macmillan nurse allocated to support him - “she was brilliant”. He was told he had an average of five year's life expectancy. He also spoke to the welfare advice team at Powys County Council who were helped him to get a blue badge. In April 2017 he was admitted to the Royal Sussex Hospital in Brighton where he was on holiday, as his tumour on his colon had worsened and an emergency operation was needed. His whole colon was removed, and he spent three weeks recovering in hospital there, and a further two weeks at home, before being able to return to chemotherapy. His recuperation was assisted by some home visits from the Macmillan nurse.

Speedy recovery

Tim puts his relatively speedy recovery down to his physical strength. This comes as a result of a lifetime of physical labour as a potter, artist, manual worker, handyman and gardener for 10 years in the North Powys area. The other factors that have seen him do so well are that the side effects to the chemotherapy have been minimal thanks to the anti-nausea treatments working so effectively and the fact that there has been no further progression in the disease - no more tumour development or spread in the lymphoma.

10 - Tim having chemotherapy

11 - Tim and his wife Sarah.

Technology and quality of life

Tim is fully aware of how lucky he is in this stability. This is not to say that he's not had his problems - a number of short hospitalisations due to infections plus some loss of teeth and hair due to chemotherapy. Tim was lucky to have been offered a Portocath system to deliver the chemotherapy.   This replaced the original PICC Line system that he had for 2+ years which   entered the body through the upper arm. The Portocath is implanted surgically under the skin in the chest and allows for a safer and simpler access to the chemical drip at the hospital on each cycle. It remains safely under the skin when not in use and is therefore not a risk for infection; also, it does not need to be removed before air travel as is the case with PICC Lines. Tim and his wife are lucky enough to have been able to travel since diagnosis including two memorable trips to Japan and Vancouver, Canada.

Art and well-being

As time went on it became clear that the hospital clinic treatment was working, Tim realised he was not in immediate danger of dying, even though his prognosis is still terminal. In conversation with his wife, doctors, friends, and his councillor at The Hamar Centre in Shrewsbury Hospital, he realised he had the opportunity to continue to make art. Tim was a potter and art teacher for most of his working life, he had his own studio in the 1980s and had taught art in schools and colleges both in the UK and USA. He still has a large collection of his works and set about creating an exhibition of all his pottery, sculpture, drawings, paintings, and other works to form a retrospective. Now having a lot of time on his hands, he has been able to create more work both digitally and using recycled materials, some of which relate directly to his illness, and the practical process of his new daily situation.

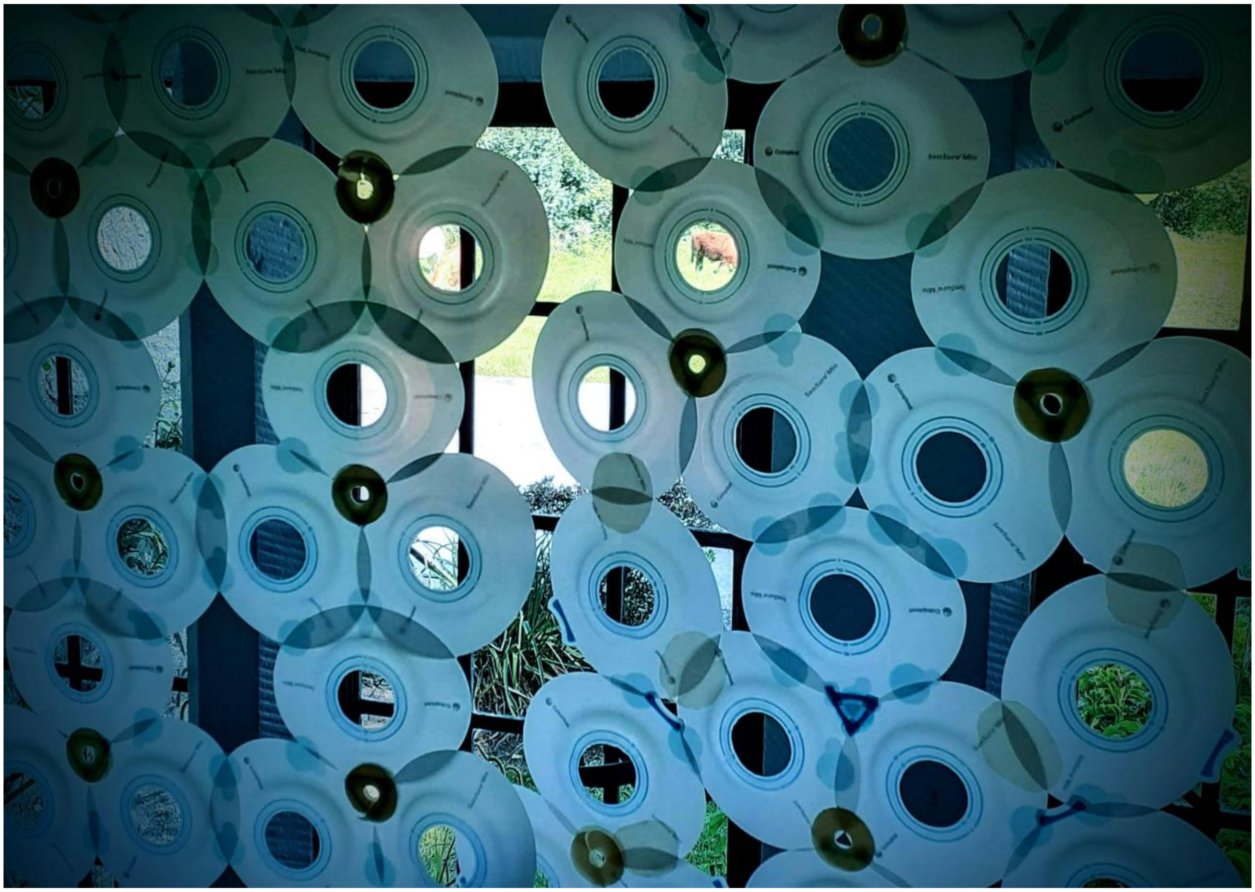
'Curtains' is the title for one of his new sculptural pieces formed from plastics discarded every day on application of his stoma bag. Curtains made of round sleeves layered to form patterns that partially hide the view from one place to the other, but also illustrate the passage of time, each sleeve being one day since the fateful operation. Tim now has many hundreds of sleeves to use in the 'curtains'. With help from the Macmillan ICJ programme, he has been able to contact local councillors who have advised on potential exhibition venues, with further good luck his retrospective will happen at The Mid Wales Arts Centre in Caersws in Summer 2021 and also some community art sessions may happen with the Ponthafren Association Charity in Welshpool.

Being able to see a goal towards which to devote your time, especially during the coronavirus lockdown was especially helpful. Tim said: ***"To be given this opportunity to share my artistic experience with the local community has been wonderful. At times the tenderness and pain in my fingertips, a result of the chemo, has made the picture framing and sculptural work all the more difficult, but also, I have a motive to push through the pain, as the achievement feels all the more satisfying."***

The key themes from Tim's story are:

- Co-ordination of Care
- Emotional Support and Care
- Relationships and communication
- Education and Information

"I am lucky to have my art to focus my time and purpose on and I encourage anyone in a similar situation to look for or revive a skill if they can, to put purpose into their time."



J's Story - How Times Change

J was originally diagnosed at 33 years of age with breast cancer some 40 years ago. She had a mastectomy – there was no chemotherapy and no radiotherapy and no offer of reconstructive surgery at that time.

She remembers only knowing one other person who had survived breast cancer at the time and found that people were embarrassed and did not know what to say or want to make eye with her.

Now aged 70+ she feels there is a much better understanding of cancer and it’s talked about more freely and openly and the whole aspect around mental health and how getting a diagnosis of cancer can impact on this is recognised.

Singing Support

When first diagnosed she was part of a group of women with cancer who used to meet up once a month and go on trips and invite speakers to talk to them. After 20 years the group disbanded – partly due to the fact that young women being diagnosed with breast cancer were getting their information online and several members of the group had died.

As someone who loves singing J joined the Tenovus choir in Llanidloes. The choir is open to anyone with a diagnosis of cancer to help them come together with peers in a safe and positive setting where they know they are not alone and can forget for an hour and a half about their diagnosis and enjoy singing together. It’s such a positive outlet. Llanidloes is one of 17 choirs throughout Wales.

Prior to Covid the choir met up on a Tuesday evening but have instead been using Zoom. It’s good but J has really missed the camaraderie of having other choir members by your side whilst you are singing. "Signing to a screen just isn’t the same." she said.

She is looking forward to being able to meet up again – even if it’s an outside set up. The choir is mixed and they have people living with various types of cancer from prostate to breast cancer.

People who come to the choir spend an hour and an hour singing hymns and songs and they forget their worries and get a real lift from the session. They know they are not alone and they are supported by choir members.

Surviving Cancer

J will soon be classed as a 40 year survival of cancer. She feels like the aim of the ICJ in Powys programme is definitely something that will benefit people following a diagnosis so that they can have an open conversation about all the things that matter most to them and get any support they need.

The key themes from J's story are:

- Practical support offered within the county
- Emotional Support / Well-being

- Relationships and Communication

Mary's Story

Mary lives in the south of the county and was diagnosed with a rare type of Lymphoma in 2016 called CTCL Cutaneous T cell lymphoma. This lymphoma has manifested itself as Mycosis Fungoides and affects her skin. Previously to being diagnosed she had suffered for many years with what everyone thought was eczema and the CTCL was only diagnosed after two skin biopsies.

Mary has been treated at the Heath Hospital in Cardiff and at the Llandough Hospital. She has both long wave ultraviolet (UVA) and short wave ultraviolet (UVB) treatment for her lymphoma. At present, Mary sees a skin specialist at Llandough every three months. This has been helpful to understand her skin condition and how to deal with it. Mary has a Cancer Nurse Specialist at Velindre (Cardiff) and also sees an Oncologist there.

She had previously been having consultations every six months with an oncologist and had to travel to said hospital. During COVID though this has changed and she has not had one face to face consultation but instead has been having telephone calls with her Oncologist from Velindre. Mary mentioned that the move to telephone consultations due to Covid had taken a bit of time to get used to but said of her oncologist and medical staff: ***"They have been amazing."***

Treatment and Travel

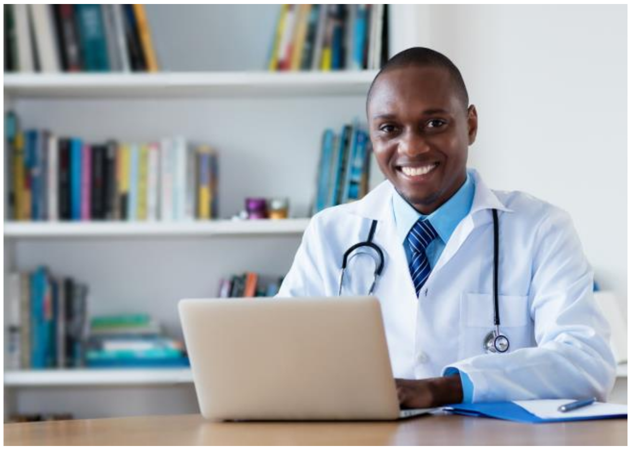
When first diagnosed, she had to travel to Llandough three times every week for treatment which lasted for a total time of around 1 minute and 20 seconds. Her round trip took her 2 hours and 40 minutes! Mary says that travel and treatment are tricky for Powys residents and travelling down to Cardiff in all the traffic is something that she knows that she has to do so she can access her treatment which is quite specialised. She says that what helps her is having someone with you to do the driving as it is very tiring.

"Some days the fatigue is worse than others and this can impact on my well-being."

Mary has never had the offer of a holistic needs assessment during any discussions with the medical staff treating her at the hospitals. She said that one of her key support networks alongside her family was with a guy she had been at school with who had also been diagnosed with lymphoma. They tended to speak and share their experiences of cancer and it was helpful to speak to someone in the same situation who understood how it felt, what it meant etc.

Regarding cancer support in Powys, Mary feels that the following need addressing:

- ***Where is there to go to for wellbeing support and therapy during treatment?***
- ***What else is there for residents living in the south of county?***



Co-ordination of Care - Hospitals and GPs

Mary knows there is an online community for cancer support via the Macmillan website and is aware of the Bracken Trust and Usk House. Everything else seems to be down in Cardiff or in England. Mary also referred to GPs often being quite removed from the care that patients received and that it'd be nice if this was better co-ordinated so that the hospital trust keeps the GP updated. Patients might then receive a courtesy phone call from their own local GP to check in and ask about their health and well-being – especially during Covid – when there should be some recognition that cancer patients are potentially now relying on telephone consultations and potentially delays in their treatment.

If not the GP, then perhaps the practice nurses could be tasked with picking up the phone and making a few calls to the cancer patients their practice serves. Better liaison between the hospital trust and the GP would definitely help. Mary was both surprised and pleased that Powys County Council had been making calls to check if more vulnerable residents who were shielding were ok during the two lockdowns.

Mary also says "*It would be good to have peer support locally, to talk and see someone. Sometimes, it feels you are making a fuss - it's almost like living a hidden life to others because you don't look like a cancer patient.*"

The key themes from Mary's story are:

- Co-ordination of Care
- Relationships and Communication

- Transport and Travel
- Practical support offered in the county
- Patient Voice and choice

Tina's Story

Tina is 54 years of age and was diagnosed with cancer of the Oesophagus in April 2017 following a scan at Neville Hall Abergavenny because she was having difficulties swallowing. Her care was then taken over by The Aneurin Bevan Health Board and she was put under the Velindre Oncology Consultant and had a series of CT scans followed by attempted chemotherapy treatment. Tina said this was *"Pretty awful. Every orifice bled and I was extremely sick and had severe diarrhoea following treatment."*

Tina is a Mum and has four children and five grandchildren and has also been a foster carer having fostered around 20 foster children. She remembers being asked by Social Services at the time if she could take on any more children even though she was having treatment and felt unable to do so. She felt that the request and the way it was handled lacked sensitivity. Even though she fully recognises that placements and foster carers are a scarce resource, she remembered thinking it could have been handled better.

In September 2017, Tina had the Ivor Lewis procedure. This involves her Oesophagus being removed and a new one being reconstructed from part of her stomach. The serious nature of operation and subsequent recovery meant she spent some time in intensive care being tube fed, receiving high doses of morphine in a semiconscious state, and being reminded to breathe by the medical team so that she didn't die.

Coordination of Care

Some patients on her ward came down with a flu like virus so Tina was sent home for her own safety and her GP and the district nurses were tasked with caring for her and they were brilliant! Her relationship with her GP was already good because of the years she had been fostering and through various treatments of children in her care, this helped greatly once she had her diagnosis, this relationship really helped with communication, really helped in terms of co-ordination of care locally.

After her operation at the Heath, she had regular check-ups at the Royal Gwent in Newport attending the Gastro Intestinal Clinic and also saw a dietician. She feels that the post-surgery support was generally good but that she was given advice that could have been more detailed. No longer registered as a Foster Carer and as her recovery appeared very good so she began a phased return to work at a pet shop locally with the help of DWP, where she had been for around a year.

A continuing cancer journey

In May 2020 Tina coughed up something that she felt wasn't right. It was like a tumour. She got in touch immediately with her GP and was sent for an X-ray locally and within 20 minutes was told that the cancer had metastasised and what she'd coughed up was a tumour from her lung. The GP said she should ring her team in Velindre which she did and was seen quickly there by the oncology team. At this point there were discussions around using a single treatment of radiation to stabilise the tumour and her care package was palliative. However, after meeting the team, because she did not present as a typical 'secondary cancer patient', the decision was made to alter the preferred treatment. Tina ended up having ten intensive radiotherapy sessions and a CT scan to decide on what was offered next. During this time “Google” became the family’s best friend.

Lactose Intolerance Impact and a Second Opinion

Tina is lactose intolerant and wondered how this was impacting on her treatment, as chemotherapy drugs are held and administered in a lactose solution. **Probably something that not many people know or realise.** The information gathered also showed links with refined sugars and processed foods. Despite the previous failed attempts, she was asked to and tried chemotherapy again which failed and made her really ill. This left Tina and her family feeling very disappointed and the decision was made to try and get a second opinion. This led to her consultant and a London consultant discussing her case, cross-referencing their knowledge, and listening to Tina's own thoughts around her diet, her lactose intolerance and the links to sugar and milk. They decided to then try a different approach which reduced the chemotherapy dosage and allowed Tina to complete the full course. The result was positive - her tumour had shrunk.

12 - Being lactose intolerant caused problems for Tina's chemotherapy.

13 - Tina went from a size 22 to a size 14.

Tina had removed all refined sugars from her diet and all processed foods and was eating a plant-based diet. Over the last 18 months she has changed her lifestyle and diet. She said she had “flummoxed” the clinicians and consultants and that she has gone from a Size 22, 16 stone to a Size 14, 10 stone 3 pounds. The CT scan showed that there was damaged lung tissue from intensive radiation therapy but the tumour had shrunk following four rounds of reduced dose chemotherapy. The London consultant felt it would be possible for the tumour to be removed. Tumours on the lung are really serious and despite Tina being told in May 2020 that she was palliative, it was agreed that she would now be offered surgery to prolong her life. She was told that there was a surgeon at the Heath would be able to take out the lower lobe of the lung and that this operation would require a 12 week recovery period.

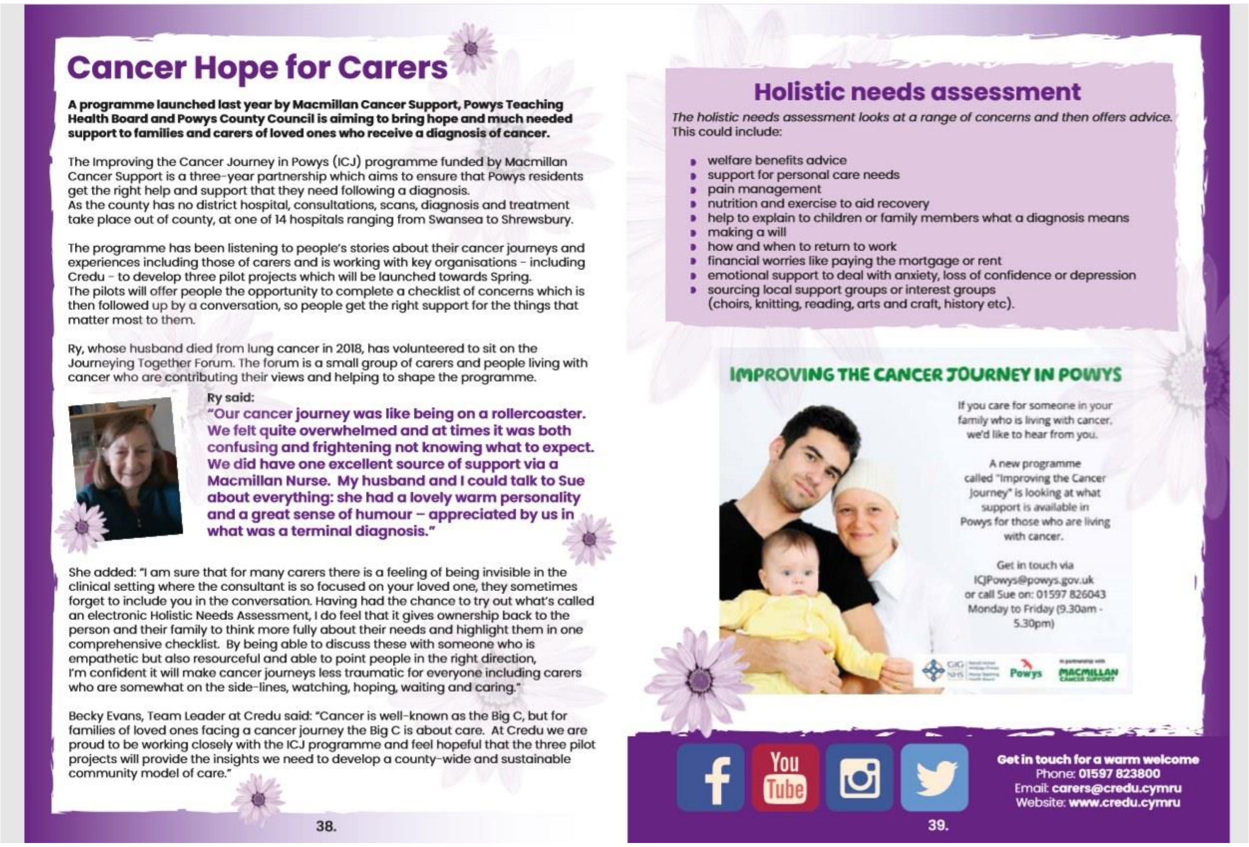
Tina decided she wanted to go forward with surgery, passed the fitness test, followed the infection protocol for Covid as the country was in lock down, and the surgery was performed in another hospital in Cardiff that was a green Covid free area. She now receives what is known as 'maintenance chemotherapy treatment' - a three weekly dose of IV medication to reduce the production of cancer cells. There is no guarantee that this will work, it is a drug that was initially trialled four years ago but Tina feels fortunate to be able to receive this treatment at the Velindre outreach centre based at Prince Charles Hospital in Merthyr.

Lifestyle Cancers and Awareness Raising

Tina says she was one of three people where she lives in the South of the county who got the diagnosis in 2017 and she’s the only survivor. This type of cancer - a lifestyle cancer - is greatly on the increase. She says that the whole topic of lifestyle cancers is really important for people to understand and that much more needs to be done to promote the importance of a good and nutritious diet which is free from refined sugars and processed foods. Media coverage in TV programmes needs to be more focused with educated professionals leading and promoting the information given to viewers rather than the latest celebrity or TV personality so that it is seen as more than a trending fad. She said having access to a Macmillan buddy for a period of time via the telephone had been beneficial. She thought it’d be good to see Usk House reopen to support people with cancer as during Covid it’s been closed and sadly the only support offered was to contact MIND, Tina felt that whilst they do an excellent job, they do not have specialities in cancer related mental health support.

The key themes from Tina's story are:

- Pre-diagnosis, diagnosis and prognosis
- Co-ordination of care
- Patient voice and choice
- Relationships and communication
- Education and information



Cancer Hope for Carers

A programme launched last year by Macmillan Cancer Support, Powys Teaching Health Board and Powys County Council is aiming to bring hope and much needed support to families and carers of loved ones who receive a diagnosis of cancer.

The Improving the Cancer Journey in Powys (ICJ) programme funded by Macmillan Cancer Support is a three-year partnership which aims to ensure that Powys residents get the right help and support that they need following a diagnosis.
As the county has no district hospital, consultations, scans, diagnosis and treatment take place out of county, at one of 14 hospitals ranging from Swansea to Shrewsbury.

The programme has been listening to people's stories about their cancer journeys and experiences including those of carers and is working with key organisations – including Credu – to develop three pilot projects which will be launched towards Spring.
The pilots will offer people the opportunity to complete a checklist of concerns which is then followed up by a conversation, so people get the right support for the things that matter most to them.

Ry, whose husband died from lung cancer in 2018, has volunteered to sit on the Journeying Together Forum. The forum is a small group of carers and people living with cancer who are contributing their views and helping to shape the programme.

Ry said:

"Our cancer journey was like being on a rollercoaster. We felt quite overwhelmed and at times it was both confusing and frightening not knowing what to expect. We did have one excellent source of support via a Macmillan Nurse. My husband and I could talk to Sue about everything: she had a lovely warm personality and a great sense of humour – appreciated by us in what was a terminal diagnosis."

She added: "I am sure that for many carers there is a feeling of being invisible in the clinical setting where the consultant is so focused on your loved one, they sometimes forget to include you in the conversation. Having had the chance to try out what's called an electronic Holistic Needs Assessment, I do feel that it gives ownership back to the person and their family to think more fully about their needs and highlight them in one comprehensive checklist. By being able to discuss these with someone who is empathetic but also resourceful and able to point people in the right direction, I'm confident it will make cancer journeys less traumatic for everyone including carers who are somewhat on the side-lines, watching, hoping, waiting and caring."

Becky Evans, Team Leader at Credu said: "Cancer is well-known as the Big C, but for families of loved ones facing a cancer journey the Big C is about care. At Credu we are proud to be working closely with the ICJ programme and feel hopeful that the three pilot projects will provide the insights we need to develop a county-wide and sustainable community model of care."

Holistic needs assessment

The holistic needs assessment looks at a range of concerns and then offers advice.
This could include:

- welfare benefits advice
- support for personal care needs
- pain management
- nutrition and exercise to aid recovery
- help to explain to children or family members what a diagnosis means
- making a will
- how and when to return to work
- financial worries like paying the mortgage or rent
- emotional support to deal with anxiety, loss of confidence or depression
- sourcing local support groups or interest groups
  (choirs, knitting, reading, arts and craft, history etc).

IMPROVING THE CANCER JOURNEY IN POWYS

If you care for someone in your family who is living with cancer, we'd like to hear from you.

A new programme called "Improving the Cancer Journey" is looking at what support is available in Powys for those who are living with cancer.

Get in touch via
ICJPowys@powys.gov.uk
or call Sue on: 01597 826043
Monday to Friday (9.30am - 5.30pm)

GIG NHS Powys MACMILLAN CANCER SUPPORT

Get in touch for a warm welcome
Phone: **01597 823800**
Email: **carers@credu.cymru**
Website: **www.credu.cymru**

Carer Insights

Listening to the views of carers has been an important part of the programme so as to understand how a cancer diagnosis for a loved one impacts on the wider family unit.

Here we share some of those stories including a short video clip of Ry talking at the launch event in September 2020 about some of the difficulties and some of the tips she'd like to share with other carers. Permissions have been given from all those shown in the video.

One of the key themes that carers often talk about is the lack of advanced care planning especially for anyone with a terminal diagnosis. You can find out more at: https://pthb.nhs.wales/about-us/programmes/my-life-my-wishes/

Ry's Story in more detail

Ry cared for her husband who was diagnosed with lung cancer back in 2018. He was terminal right from the word go. They knew straight away that something dreadful had happened. They had gone out one evening and her husband announced that he could not drive the car home because he wasn't feeling well. His arm had swelled up and he was in pain. He subsequently died 16 months later.

Ry described the cancer journey as being on a rollercoaster – a cancer rollercoaster – with appointments galore day after day. She felt very much invisible and unheard on numerous occasions by the clinicians who were dealing with her husband and giving him information about his prognosis that he was struggling to digest. Her husband seemed completely bewildered by the whole thing and he went silent, clammed up on her and others and she found herself having to advocate and negotiate on his behalf all the way for him and what he wanted.

Relationships and communication

In their own relationship she also felt like she was having to tread a very careful tightrope – it was a delicate situation trying to sustain the communication channels and it was nerve-wrecking trying hard not to say the wrong thing to her husband. Painful and upsetting to know you are alive and the person you married to is dying and that they know it and you are both trying to consider all the things that need to be said/done/discussed/not discussed/are important/aren't important etc… Ry wants to ensure that carers whether spouses, siblings, another family member, or a family friend are heard and recognised by clinicians more as the people who pick up the pieces following an appointment/treatment/prognosis etc… Ry said:

"Carers should have an opportunity for a private discussion with clinicians."

Ry had help from her family to support her husband. With five children and 13 grandchildren Ry organised family get togethers. Two of her children who live in Australia came over to see their dad. Friends of her husband were contacted and got him out and about. She managed to get her husband to start a blog and write about his experiences which was really good. It created an opportunity for him to express himself when words failed him verbally and provided a way for his friends to chat to him over email.

A Lonely Job

Caring is a very lonely job and Ry feels that there are few joys in caring overall. There is a need in her view for a new term to help people understand what a carer does. A family carer might better describe the role. You have to take decisions along the way on behalf of the person you love, decisions that are tricky to live with. Carers are often unsung heroes in our communities. Plenty of carers in Powys are potentially in their 70s and 80s and busy looking after their spouses or other family members. At one point, her husband was admitted to Morriston for five weeks and nearly died. He had lost all his body fat and muscle after this time and she felt that the best place for him to be was at home. She battled the medical people at the hospital to try and get them to understand that what her husband wanted and needed was peace not pressure!

Too slow, too late

Basically, most of the treatment was much too slow and too late. There was a real battle to as she put it "unhitch us from the medical teams." who kept offering treatments too late. An inappropriate operation was attempted during his last month but at that point in time no treatment was going to help, and he just wanted to rest. With her daughter, she managed to get him to write a letter to the surgery explaining what he wanted to happen in terms of his "end of life" care. The local surgery stuck to it and he died in Ystradgynlais hospital which was what he wanted in 2019.

Journals and Appointments

One of the things that Ry did during the time they had was to keep a journal about everything that happened. This really helped her express her thoughts and feelings and it has been quite cathartic to re-read. She would recommend doing this. Her daughters also set up a What's App group for family members so they could discuss things without their mum needing to be involved. She felt that it had been really important that she and members of her family had attended all the appointments with her husband so that she/they was there with him hearing the prognosis, asking questions etc especially when he could not and seemed bewildered.

She would tell anyone who is living with cancer to take someone with you to any appointment. It helps because they can then relieve the pressure off the person with the diagnosis having to inform everyone else and ask questions, check facts and support that person by just being in the room hearing the information at the same point in time. The PLWC may not take it all in for obvious reasons.

The key themes from Ry's story are:

- Pre-diagnosis, diagnosis and prognosis
- Co-ordination of care

- Emotional support and care
- Patient voice and choice
- Carers rights and voice
- Relationships and communication
- Advance care planning
- Education and Information

https://sway.office.com/Zgp1uluVcaA9dI5Z#content=EeRcWJR3UWbFq7

14 - Ry speaks about her role as a carer at the launch of the ICJ programme - September 2020.

More Carer Stories

J's Story - Lung cancer

R's Story - Stomach and pancreatic cancer

N's Story - Secondary breast cancer

L's Story - Bladder cancer

J's story

J’s mum lived in mid Powys and was diagnosed with lung cancer in early July 2020. She was 92 years of age and had not been feeling quite ‘right’ for a long time but hadn’t wanted to pester her GP partly because of Covid. In November 2019 she was admitted to Hereford hospital and a chest X ray was taken as a matter of routine. This was then sent to Australia for a radiographer to check.

Fact Check - It's an interesting and little known fact that reciprocal arrangements are in place when hospitals in the Northern hemisphere are busy. As the southern hemisphere is in the summer season the *hospitals are less busy and thus there is more capacity to support the winter increase in patient numbers in the UK and other countries.*

Patient Choice

The X-ray flagged up a spot on her lung and was sent back to Hereford hospital. This result should've triggered a CT scan, but it didn't and J's mum was discharged. She continued to feel unwell and in July 2020 was sent for another X-ray and a CT scan which showed a tumour on her lungs. The cancer had also spread to her liver. J's mum was told that her age wasn't a barrier to treatment. However, his mum refused treatment with the prognosis that she had approximately six months to live. At this point she was discharged from the hospital and said she'd like to be at home and stay there for as long as possible. One of the positives of knowing the prognosis was that the family were able to take their mum away on a short holiday on a canal boat before she died.

15 - A holiday on a barge was something J's mum enjoyed.

Co-ordination of care and Advance Care Planning

Although wanting to die at home, a hospice wasn't ruled out, but on returning home this is when things became quite difficult in terms of the support and care. J and his brother and sister moved in with her on a 24hr rota basis to try and support their mum but, they all felt like that they didn't entirely know what they were doing or should be doing. The whole handover from the hospital trust back to Powys was very poor. There was lots of chasing going on to find out what support was available. J's sister who as a retired Social Worker was very aware of the system, still struggled to get anything progressed. There is definitely an issue regarding the co-ordination of care between the NHS and social services. Having requested an assessment, Social Services took five weeks to get back to them. It was dreadful and when a social worker was finally assigned to do an assessment, she then rang to say the case had been wrongly assigned to her, she was busy/at full capacity and it needed to go back into the system!

The family managed to get some support from the district nurses for pain management as his mum's condition got worse and they were fantastic. However, as family members wanting to be respectful and ensure their mum had her dignity intact, they felt she needed domiciliary care support and personal care support too yet it seemed as if a decision had been taken that the family were coping and thus support wasn't critical.

The Hereford consultant visited his mum at home a couple of weeks before she died and she asked about what care provision was being provided. While she was there the family had a call from a social worker which highlighted further confusion about the process. The consultant joined the call and said that if there was no support forthcoming then she would transfer J's mum back into the NHS. Overall, it was a difficult time. J said it does feel like if a person has some family support there is a reluctance for additional support to be offered in terms of personal and domiciliary care. That may be ok to start with, but if someone is dying there does come a point in time when it is not possible for family members to deal with the personal care needs and help that should be given and given promptly.

Eligibility for care

J said the threshold for eligibility and care and support based on the prognosis given was confusing. The best support given to J's mum alongside the district nurses and NHS Occupational Health, came from the carers at St David's hospice. J's mum needed more intensive medical interventions and support and the charity came out and stayed with her overnight over the last few days. J noted that even if you have the resources and wanted to pay for someone privately to look after your relative, it's really difficult to find anyone suitably qualified or willing to do so and the charity were a godsend.

It's ironic that finally after lots of badgering and seeking support, his mum died an hour before the carers arrived! This was in early September 2020.

J cannot remember his mum being asked if she'd like to complete the "My Life, My Wishes" documentation and no HNA was offered but this may have been because of her prognosis. He's not sure. He does feel that having one person – a link worker – to help pick up and co-ordinate and consider all the things that might be required to improve someone's quality of life especially at end of life is so important.

The key themes from J's story are:

- Pre-diagnosis, diagnosis and prognosis
- Co-ordination of care
- Advance Care Planning
- Relationships and communication

- Practical support offered in the county
- Information and education
- Carers rights and voice
- Patient voice and choice

'My Life My Wishes' is an Advance Care Plan or Statement of Wishes and helps people think about their future needs. It's one of the themes that came out via the stories captured. It's a paper document that stays with you and can be shared and uploaded onto your GP's IT system. You can add to it and change it over time.

R's story

R shared her cancer experience of supporting her husband when he was diagnosed with metastatic stomach cancer in his pancreas. He was diagnosed at 59 years old and died aged 60. He was very fit and a keen cyclist and had always been well and in good health. They have 3 adult children, 2 living at home and 1 in England.

R is now 58 and continues to work part time at a local supermarket and 'keeps busy'. R responded to the ICJ advert to talk to programme team as she felt it might help to 'unburden' and "put her feelings to bed", so that something positive could come from their experience and so that her husband's death is not in vain. Her daughter had seen the ICJ advert on Facebook and suggested her mum ring up.

Prognosis Language Confusion

R expressed how poorly she felt her husband's condition and prognosis had been communicated. R heard the words 'Palliative Care' but didn't know what this was, or what it meant, and consequently had not realised how ill her husband was. They were referred to the Macmillan Welfare Benefits Advisor for PIP(Personal Independent Payments) but she hadn't realised at this point that her husband wasn't expected to live more than six months and the need for urgency around this benefit provision. R felt there was not enough advice around what this all meant and needed leaflets to read up on things.

R's husband was treated at Prince Charles Hospital, Neville Hall and at Velindre involving blood tests and chemotherapy on Fridays. R worked part -time throughout but they managed somehow to make appointments. They did have St David's Hospice Care at Home for 1-night care. R felt angry for quite a long time about their experience and the effect on all the family.

"People ask if you want help, and yet you feel it's the last thing you want so I didn't take any support."

R mentioned how her husband’s Mother died of Pancreatic cancer and how this knowledge makes her worried for her children, whether this cancer is genetic in their family. She's not sure how to access this conversation with GP or family, where to go to talk about her fears and is finding it difficult generally to talk about these things.

The key themes from R's story are:

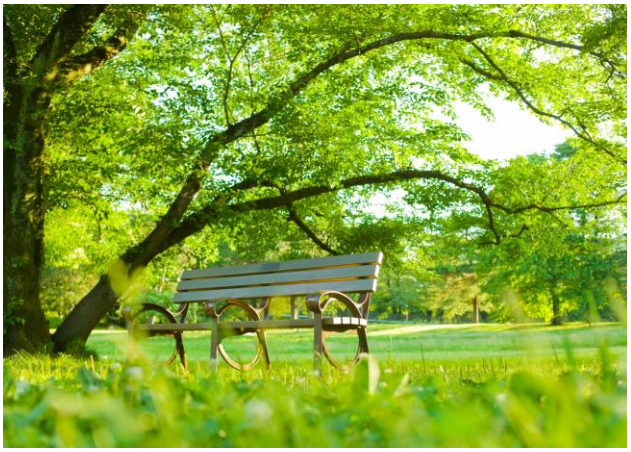
- Pre-diagnosis, diagnosis, and prognosis
- Emotional Support and Care
- Advance Care Planning
- Practical Support offered in the county
- Education and Information

N's Story

N is a young man aged 21 whose step-mum died from secondary breast cancer in 2019 aged 47 years of age. She was treated in hospital where the care and the nurses were good. However, N knows that she would have preferred to be at home and to die there and not be in hospital at all. He says the reason for this would be that she would have felt safer with her family.

N who was aged 19 at the time spent a lot of time at the hospital staying overnight so as to be close to his step-mum and provide support and translation. The hospital did also get a female interpreter to help support their communication as his step mum's first language wasn't English. Because his step-mum loved being outside N often took her out in a wheelchair for a change of scenery. When at home she used to go out for walks in the community.

She was first diagnosed with breast cancer whilst living in Jordan having left Syria because of the war. When the family relocated to the UK, she was recovering from her mastectomy. However, unfortunately the operation to remove her breast hadn’t completely removed the cancer tumour and she was diagnosed with secondary breast cancer. The family were and have been supported by EYST and the Syrian Vulnerable Person Relocation Project Officer since being relocated to the UK and have settled fairly well in the county and feel that most people have welcomed them.



16 - N's mum liked being outside.

N says that for him the hardest part was when the nurse told him his step-mum had died and he kept asking her to do something, to resuscitate her, and she said she couldn't because it was too late. N says it's been really hard for all of them as a family but for his Dad in particular who is feeling quite lonely a lot of the time. He says he and his brother are young and have a life to lead and that he is trying to support his Dad as best he can.

He can't remember anyone in the family being offered any additional support or a HNA. He says if it had been offered it might have been helpful.

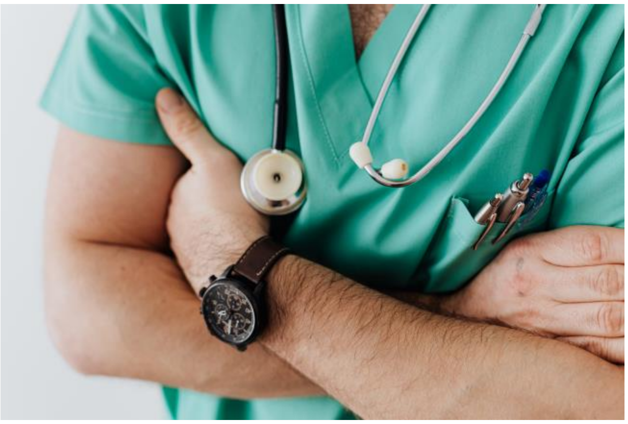
The key themes in N's story are:

- Advance Care Planning
- Relationships and Communication
- Patient Voice and Choice

L's story

L, cared for her father-in-law (D) who was diagnosed with a bladder tumour initially in 2017 at Hereford hospital. He was told that the tumour was in a position that meant there was nothing that could be done – no operation – and that it was slow growing. Her father-in-law was 91 years of age at the time. He was coping well overall at this point with some minor and small bleeds occurring every so often.

In 2020 things deteriorated. In the April, his wife died. She had Alzheimer's and was in a home and D visited her every day. However due to Covid he hadn't been able to see her since lockdown and was very upset. It was a big blow. A few months later he had a stroke and was admitted to hospital but recovered and came home. In August, L had to call an ambulance as he had a big bleed and was very distressed. This was unusual and he was taken straight into Hereford hospital. The hospital fitted a catheter thinking this may help him because the tumour was potentially making him want to go to the toilet more and this could help him. He was then discharged from hospital with a letter saying that there might be an option for him to have some palliative radiotherapy and the hospital would be in touch.



On that first day of discharge once back home D had a visit from a district nurse. There appeared to be some confusion around whether they should be changing the catheter or if D needed to go back to hospital to have it changed. They said they'd need to check. L said that for the first few weeks of September they were trying to ensure they emptied the bag and kept everything clean, but the catheter leaked and was also getting blocked, and they ended up calling the district nurses quite a bit to try and help. They were told that the nurses would visit if they needed them but not on a daily basis. L also reached out to PAVO and the community connector service who listened to her situation and tried to help by raising her concerns with the relevant people.

Having not heard anything back from the hospital about the radiotherapy treatment L started to chase this up by ringing the GP who sent a letter on D's behalf. L also chased the hospital on at least two occasions and was finally told someone would look into it. This was on 21 September – nearly a month after he'd come out of hospital.

Blame Game

L thinks there was a bit of a blame game going on between urology and oncology about who was picking up the radiotherapy option. A telephone appointment took place in early October 2020 with the urology consultant who then referred the details onto the oncologist in Cheltenham. He arranged for an appointment for D on Monday 12 October.

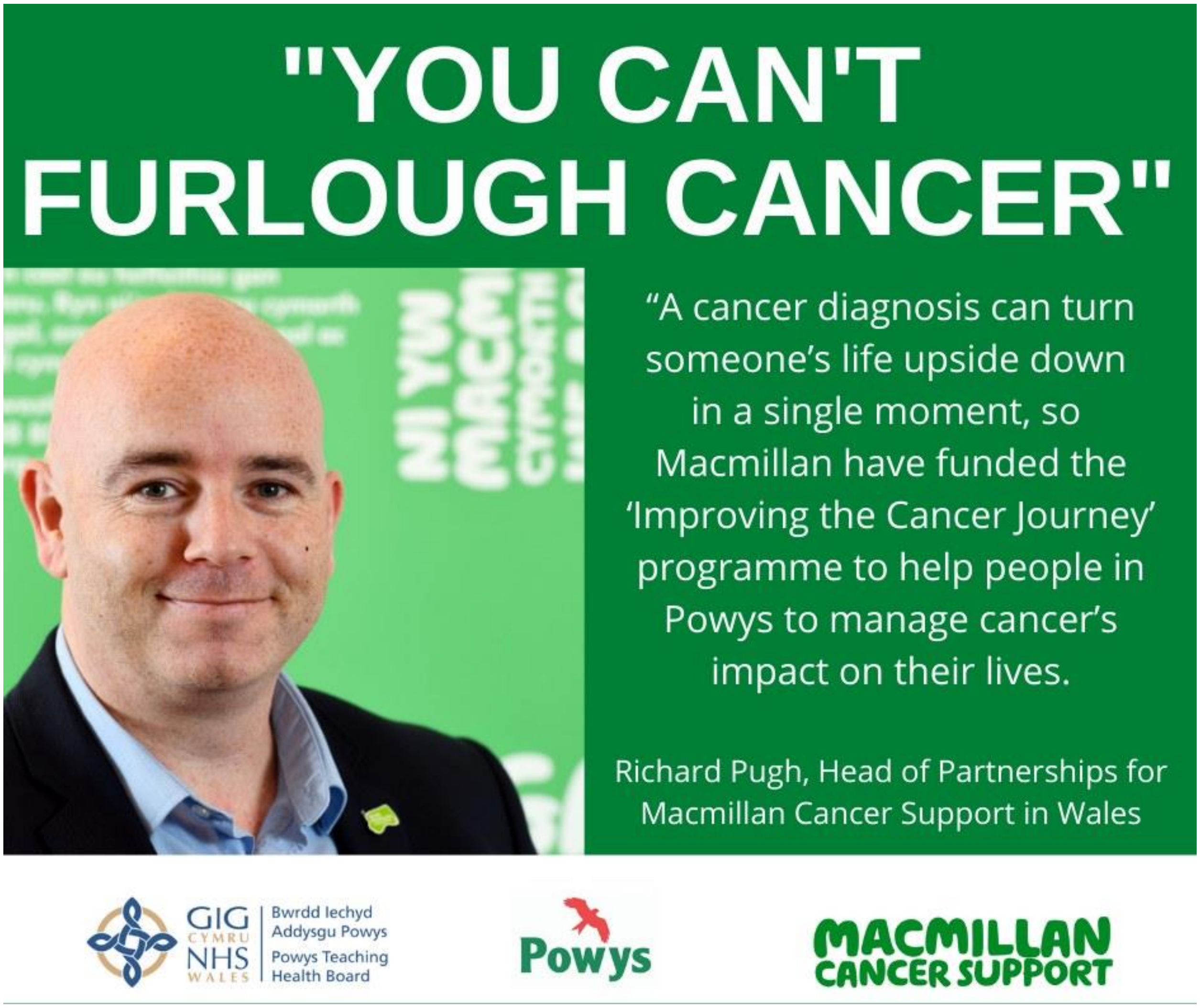
However, D never made it to this appointment because on the Thursday before he was in absolute agony and was passing more blood than urine. The district nurses came out during the day (L called them for help) and they prescribed paracetamol and washed out the catheter with saline water but said they couldn't really do anything more and perhaps he should be readmitted to hospital for care. L ended up calling Shropdoc early that evening and D ended up being admitted to hospital. He didn't want to go in, but L and her husband felt it was for the best. He was admitted on the Thursday evening. He was placed on a ward the next day but with Covid wasn't allowed any visitors. He spoke to them on the telephone on the Friday. On the Saturday he seemed a little better but on Sunday they received a phone call saying that they could visit him because he was getting worse and was unlikely to recover. He was taken off his drip and died in the early hours of the Monday morning.

His death certification said he'd died from sepsis and hospital acquired pneumonia alongside having congest cardiac arrest and advanced bladder cancer. L said that although she couldn't fault anyone in particular, she wonders if her father-in-law had been offered the radiotherapy sooner, this could have helped and prolonged his life. She feels the co-ordination of care is tricky and people do fall between the gaps. She said no one offered D a HNA and that there appeared to be some last-minute support being offered via a Macmillan Nurse but it was too late. She didn't have any contact with or any referral into the end of life PTHB services. She assumed her GP would've done this if required.

Overall the family feel that the whole hospital discharge could have been better in term of co-ordination with the Powys district nurses who didn't know if they should be changing the catheter or not. Lots of confusion on lots of levels.

The key themes from L's story are:

- Co-ordination of care
- Patient voice and choice
- Carers rights and voice
- Practical support offered in the county
- Advance care planning
- Relationships and communication



"YOU CAN'T FURLOUGH CANCER"

"A cancer diagnosis can turn someone's life upside down in a single moment, so Macmillan have funded the 'Improving the Cancer Journey' programme to help people in Powys to manage cancer's impact on their lives.

Richard Pugh, Head of Partnerships for Macmillan Cancer Support in Wales

IMPROVING YOUR CANCER JOURNEY IN POWYS

If you are living with cancer, we want you to be able to live your life as fully as you can, by offering you practical, physical, emotional, spiritual and/or social support so you can achieve what matters most to you.

We want to involve you, listen to you and find out what matters most to you so that together we can develop support services that meet your needs.

To find out more or get involved contact:

Sue Ling
ICJ Macmillan Communications and Engagement Officer
ICJPowys@powys.gov.uk
or 01597 826043 (Mon - Fri)

Thank You and More About the ICJ Programme

The ICJ in Powys programme would like to thank all those who have been willing to share their cancer experiences in this compendium of patient stories.

As you have read, the experiences are mixed. Some people have received excellent care and support both in a hospital setting and within our county from their GP, district nurse or a third party provider like the Bracken Trust. For others the journey has been confusing, stressful and lacking whether as a person diagnosed with cancer or a family member caring for a loved one.

By listening to these stories, we hope to address these gaps and shape a service that fits the needs of our residents. We believe the launch of the pilot projects with the offer of a holistic needs assessment at the point of diagnosis will begin to improve the cancer journey and quality of life for our residents.

We are pleased to say that three of the pilots involve our third sector partners

- The Bracken Trust
- Credu
- Powys Association of Powys Organisations via their Community Connectors service.

Powys Teaching Health Board and Powys County Council are working to embed the holistic needs assessment into their systems to support patients, carers, and residents with a diagnosis.

If you'd like to find out more you can....

e: ICJPowys@powys.gov.uk

t: 01597 826043

w: https://www.powysrpb.org/icjpowys

And, if you are reading this and have recently been diagnosed with cancer and haven't been offered a holistic needs assessment you can request one through our partners. See adverts below for more details.

If you'd like to share your story and help us better understand what it's like living with cancer or being diagnosed in a rural county like Powys, please call Sue on the number above.

IMPROVING YOUR CANCER JOURNEY IN POWYS

If you are caring for a family member who has recently been diagnosed with cancer and would like to chat about how you are feeling, and what support might be available to help you please get in touch with Credu.

As part of a Macmillan funded programme, nine Credu outreach workers, will be able to offer you what's called a holistic needs assessment which results in a tailored support plan connecting you to the right support, information, and advice to improve your quality of life.

This could be around your own well-being as a carer, supporting your loved one's emotional and practical needs, respite support, eligibility for benefits or how to juggle work commitments whilst caring.

Call Credu (formerly Powys Carers) on:

01597 823800

carers@credu.cymru

Monday to Friday, 9:00am to 5:00pm

Find out more about the Improving the Cancer Journey in Powys programme at:
https://www.powysrpb.org/icjpowys

IMPROVING YOUR CANCER JOURNEY IN POWYS

If you are living with cancer and would like to chat in confidence about how you are feeling and what support might be helpful to you, please get in touch with the Community Connector Service.

As part of a Macmillan funded programme, two trained connectors are on hand to offer you what's called a holistic needs assessment which helps you consider your key needs and connects you to the right support, information, and advice to improve your quality of life.

Whether it's about welfare benefits, work considerations, what local support groups exist or thoughts about revisiting a past hobby to boost your well-being, Hayley and Clare are on hand to talk about what matters to you.

Hayley and Clare - ready and here to help

Call the Community Connector Service on:

01597 828649

community.connectors@pavo.org.uk

PAVO - Powys Association of Voluntary Organisations

Find out more about the Improving the Cancer Journey in Powys programme at:
https://www.powysrpb.org/icjpowys

*17 - **The [Macmillan Support Line](https://www.macmillan.org.uk/) offers free, confidential support to people living with cancer and their loved ones. If you need to talk, we'll listen.***

It's open 7 days a week from 8am to 8pm and you can call 0808 808 0000, email or chat online by clicking on this link. https://www.macmillan.org.uk/