

Our lives on hold...

Impact of NHS waiting
time on patients' quality
of life



CYNGOR IECHYD CYMUNED
COMMUNITY HEALTH COUNCIL

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About Community Health Councils

This report has been produced by the Board of Community Health Councils on behalf of the 7 Community Health Councils (CHCs) in Wales.

CHCs are the independent watch-dog of NHS services within Wales and we seek to encourage and enable members of the public to be actively involved in decisions affecting the design, development and delivery of healthcare for their families and local communities.

CHCs seek to work with the NHS and inspection and regulatory bodies to provide the crucial link between those who plan and deliver the National Health Service in Wales, those who inspect and regulate it, and those who use it.

CHCs maintain a continuous dialogue with the public through a wide range of community networks, direct contact with patients, families and carers through enquiries, our Complaints Advocacy Service, visiting activities and through public and Patient surveys. Each of the 7 CHCs in Wales represents the "Patient voice" within their respective geographical areas.

This report brings together a range of patient stories and reflections about the impact that delayed treatment has had on themselves and their families. They represent a small percentage of those waiting for NHS treatment in Wales. We recognise that everyone's individual experience will be different.

Introduction

Health boards and trusts regularly judge their performance in terms of Referral to Treatment Times (RTT) against a set of targets described in weeks. It is regularly reported in the media that targets are missed or that waiting times in Wales are worse than in other parts of the UK.

Reviewing performance simply against figures can provide a useful indication. It does not provide a picture of what it is like to wait for treatment, perhaps in pain or with reduced mobility. Neither does it capture the wider and sometimes life changing impact on individuals, families and communities.

The 26 and 36 week targets were last met in Wales in August 2010. We have seen a welcome improvement in waiting times in Wales over the past year (at the end of February 2018, 87.3% of patients in Wales had been waiting for less than 26 weeks).

Nevertheless, the failure to meet targets has become an accepted norm. The real life implications of this can be devastating. It is important that decision makers look beyond the numbers when judging performance and deciding what to do about it.

This report aims to capture the impact that long waits have had on a range of people across Wales. We believe their stories demand action and challenge Welsh Government to take action to end long waits.

What we asked

We simply asked people to tell us in their own words how waiting for treatment was affecting their life. These people came to us through a variety of sources;

- Advocacy Service clients
- Engagement events
- Social Media
- Print media articles about this project

What we heard

Coping with pain

“At that point I was in agony, and could only walk a few yards as the pain was excruciating. My Consultant could see how much pain I was in and apologised for the delays, but said the waiting lists were never ending”.

Most people we heard from told us they were in pain, and for some patients pain affected their quality of life very substantially.

For some people long term use of strong pain killers was a cause of concern. People worried about side effects, over reliance and reduced effectiveness. Long waiting times for many procedures coincided with long waiting times for Pain Management Clinics (up to 2 years in some cases).

Without the help of Pain Management Clinics, patients with drug intolerances found it extremely difficult to get any form of pain relief. Access to non-drug methods of coping with pain, such as hydrotherapy and physiotherapy were seen as similarly limited.

We heard about what might be described as a catch 22; being told you do not meet the criteria for chronic pain management as there is a known and available surgical intervention that would address your problem completely.

Mobility

“I cannot walk any distance without the aid of two walking sticks and if I have to wait until the summer of 2018 then I

can see me becoming housebound, which I know will have an impact on my mental health”.

The inability to carry out day to day activities that most people take for granted was a major issue for many people. Some people we heard from were carers and were no longer able to provide the care needed by their spouse or child.

Falls were a major issue;

“I managed to trip and fall in the house three times due to my poor vision, I must admit I began to feel really down as I had lost my independence and felt isolated and cut off from my normal daily activities. I became totally dependent on my husband which in turn impacted on his independence”.

Loneliness & good mental health

“The present situation is causing me a good deal of stress. I am getting periodically depressed, my marriage is suffering and I am no longer aware of what action I can take to resolve the situation”.

Many people told us that the combination of decreased mobility, pain and ill-health removed them from their usual activities and support networks and left them feeling isolated and lonely.

There is also a strong effect on mental health. Some people told us they feel powerless and distressed by waits of 100 weeks⁺. We heard that for some, this was made worse when their estimated treatment times kept getting extended.

Those who had retired and were looking forward to spending more time with partners and family and developing hobbies and leisure activities told us the pain and stress of waiting for an operation had considerably reduced their quality of life;

"I do not suffer from depressive personality, I always look on the bright side of life but I must admit the last six months of waiting became very trying.

I could not go out in the garden if there was bright sunshine, indoors, the curtains and blinds needed to be drawn in whatever room I was in order to exclude bright light or sunshine.

Simple things like watching the television became very uncomfortable. I had great difficulty in reading books or newspapers, I could not use my computer without great difficulty".

Private Treatment

"I had my hip replacement on 1st November 2017 at a private hospital, close to where my daughter lives in England, at a cost of £10,500. If I had known I would have been waiting for this since I was first referred in October 2015, I would have had it done privately long since".

Intolerable levels of pain and mobility problems had led to some people paying for private treatment even though they could ill-afford it. Usually this was for an initial appointment with their NHS Consultant but some had gone on to pay for total joint replacements when waits became unacceptably long.

Loss of dignity

"I have now been suffering the indignity of having to wear a catheter for almost 12 months. During this period I have suffered five urinary tract infections. Initially the district nurses changed my catheter at the local surgery but they

began to have problems and now the catheter has to be changed at the hospital”.

Some patients commented on the indignity of having to rely on others to carry out intimate personal care because they could no longer do it for themselves.

Being unable to maintain personal appearance was also a concern for many.

Relationships

People reported a severe effect on family life. Many older people had commitments providing care for grandchildren. Inability to carry this out had major financial implications for the entire family. People also told us about the emotional impact of missing out on what should have been a source of happiness and satisfaction and feelings of guilt that they are not contributing to family life;

“While I was waiting the pain in my breast got worse and worse... It meant I couldn’t play with my grandchildren as I normally would because it was just too painful to lift them up or have them jump on me”.

Several people highlighted that constant pain and fear had led to being short tempered and “grumpy” with close family members.

Work & finances

Not all those waiting for procedures such as joint replacement, cataract and prostate surgery were retired. Many people told us about significant effects on their work and careers. Patient R is just 25 and facing an 85 week wait for shoulder surgery;

“Whilst most 25 year olds are career building, I cannot seriously consider any career development opportunities at

work as, instead, I am struggling to hold on to my job because of my health problems. I fear that in the longer term, even if my shoulder problem is resolved, my working record represents me as an individual with a 'sickness' problem rather than a capable individual willing to work hard and this has the potential to have life-long implications.

Others have had to take retirement while waiting because of on-going problems;

"I'm retired now but I had been working for a supermarket. My employer was very supportive while I was trying to continue working but I was quite restricted in my ability to undertake any duties that involved lifting. It was clear from meetings with my managers that they were running out of patience so I decided to retire".

Sickness benefits do not take account of long NHS referral to treatment times and we heard how this can result in great financial hardship.

"I now have a date, for mid-January 2018. The length of time the process takes does cause financial issues. Sickness benefit is only given for one year, so I have been without financial support since July 2017".

Co-ordination of NHS care

Many people told us that they have to act as their own case management co-ordinators. This is particularly true in areas such as cancer care where tests need to be done in a particular order and perhaps at a variety of locations. People told us that they spend a significant amount of time contacting different departments and liaising with consultant's secretaries to ensure things go smoothly.

Information

Lack of information on many aspects of their care was an important issue for most people.

There is a need for greater communication between the NHS and those waiting for operations, without regular communication people told us they felt abandoned;

“...she has just been left to suffer in this way for months on end. As I say, it feels as though she has just been dumped”.

“Harm” caused by waiting

Many people waiting for treatment worried that waiting in itself would cause irreparable damage and make the eventual treatment less successful.

“...the extra pressure and pain I am putting my body through because of my left knee is causing further problems and issues with my mobility”.

Holidays

People told us they had been asked to cancel holiday plans when they had been listed for an operation– even though they felt there hadn’t been any realistic prospect of having the operation any time soon. This causes unnecessary financial loss and hardship;

“Normally we would have been away over the winter and the sun and warmth offer some respite from the pain. Having been told not to go away and missing this much anticipated break, we are both upset to realise that we have waited around for nothing”.

Our Stories

The following stories are an example of what we heard from people affected by long waits for treatment, as they described it.

Patient A

I am writing to you regarding a complaint I have regarding hospital waiting times. I have currently been waiting 51 weeks for hand surgery for removal of a very large ganglion. I rang this morning to be told there is at least another 30 week wait.

I have also been waiting 41 weeks for urgent wisdom teeth extraction as I daily have severe toothache and jaw ache which is preventing me from eating correctly. I understand that, if neglected, wisdom teeth can fuse to my jaw bone which will cause lots more problems. I've been told it will be at least another 40 weeks to see a consultant then it will be another long wait until surgery.

The health board have been in contact with me advising that they cannot do anything about the ridiculous waiting times. Apparently they can't afford to fund my treatment elsewhere even though it clearly states on all NHS material I have a right to be seen and retrieve treatment within 36 weeks of referral. This is not acceptable and I want the NHS held accountable for my suffering.

Patient B

In November 2016 I was admitted to Hospital for bladder retention and was fitted with a catheter. It was later discovered that I would need a prostatectomy and this should have been done in February 2017.

I heard nothing and contacted the Urology Department in March. They said my operation had been delayed and would probably take

place in August or September. Following this I receive a letter asking me if I still required the operation. I wrote to the Concerns Team of the hospital expressing my dismay and they informed me that the operation should be done in October.

I received a letter telling me the operation would take place on 23rd October. I attended a pre-op appointment a week before and on the day attended the arrivals lounge and went through the usual procedures and waited to be called. At around 3.35pm I was called into a cubicle and told the operation had been cancelled.

I have now been suffering the indignity of having to wear a catheter for almost 12 months. During this period I have suffered five urinary tract infections. Initially the district nurses changed my catheter at the local surgery but they began to have problems and now the catheter has to be changed at the hospital.

I feel there is little concern given by the hospital to my health and well-being. I fully appreciate that more serious cases than my own must take priority but to have a twelve month break in treatment is stretching things a bit far.

The present situation is causing me a good deal of stress. I am getting periodically depressed, my marriage is suffering and I am no longer aware of what action I can take to resolve the situation. I am retired and my wife and I travel a good deal, these trips are spoilt by frequency in having to use a toilet. I also have a worry as to the effect 12 months of catheter use will have on my bladder.

NOTE – the patient is still awaiting his prostatectomy – recently told it might be “sometime in 2018”

Patient C

Initially I saw my Consultant privately in early 2015, following a referral from my GP, and paying myself to avoid waiting the 6 month

wait to see him on the NHS as I had quite severe pains in my groin, which I knew were related to a failing left hip. The Consultant said he would arrange an MRI Scan, but there might be a wait for that.

Three months later, I had an MRI Scan, which confirmed the diagnosis that I needed a replacement left hip. I received a letter from the Hospital on return from holiday two months after that requesting me to make an appointment for Physiotherapy, I wasn't sure what this was for or who had requested it, and when I asked the Physiotherapist, he said my Orthopaedic Consultant had requested it to see if the acute pain was coming from the hip or the tendon. He said he was going to inject whichever site it was, to give me some relief whilst awaiting a hip replacement.

After a few physiotherapy sessions, the physiotherapist confirmed that the pain was indeed coming from my left hip and said there was no point in continuing now that we knew where the pain was coming from - I could have told him where it was coming from!

I heard nothing more, despite the Consultant's Secretary on several occasions, until I had a letter to go for a pre-op on 12th January 2017. I asked what the pre-op was for, and was told it was for an injection into my left hip to alleviate the pain whilst awaiting a replacement.

On 11th February 2017, I was admitted to hospital and informed by my Consultant that he would give me an injection into my hip, and also an injection into the tendon of the left hip under general anaesthetic, in the hope that these would reduce the pain whilst awaiting a hip replacement.

I returned home and had slight relief for a couple of days, then the severe pain returned, and was now all down my left leg and into my foot, making it very difficult to walk. I thought this was strange, as injections do usually offer some respite, having had them in the past prior to surgery.

I saw my Consultant on return from holiday on 16th March 2017 and told him I was in severe pain, which he could already see as I walked in. He then informed me that on 11th February he had only injected the tendon, and not the actual hip joint, which I found quite annoying as it meant yet another procedure with a general anaesthetic.

On 21st March, I was again admitted to hospital and had an injection into my hip joint under a general anaesthetic, which I assumed would give me some relief from the now excruciating pain I was suffering. The effects of the injection lasted only 3 days, and I rang my Consultant's secretary to ask her to let him know.

On the 18th May 2017, I saw my Consultant at the hospital. At that point I was in agony, and could only walk a few yards as the pain was excruciating. My Consultant could see how much pain I was in, and apologised for the delays, but said the waiting lists were never ending. He told me that I was on the URGENT list and it would probably be "*towards the end of the year*". This was very disappointing to hear, but at least there was a light at the end of the tunnel, or so I was led to believe.

In the following months, I rang my Consultant's secretary regularly to say that I was available at short notice, should there be any cancellations. This was on my GP's advice, as I was now on very strong painkillers every 4 hours as prescribed by my GP. I was told there are very few cancellations, but she would make a note on my file. At that point, she did say it may well be November/December for my operation.

On return from yet another holiday in a wheelchair in October 2017, I rang my Consultant's secretary yet again, just to confirm it was going to be November/December, only to be informed, no, it was more likely to be May/June 2018. As you can imagine, this was very disappointing news, and although I cannot afford it, I decided I had

to have the operation as soon as possible, as my life was becoming impossible and very dependent on others.

I had my hip replacement on 1st November 2017 at a private hospital, close to where my daughter lives in England, at a cost of £10,500. If I had known I would have been waiting for this since I was first referred in October 2015, I would have had it done privately long since.

My GP was very, very annoyed that I have had to pay, and said I should write to the Health Board and the local MP, as it is a national disgrace that anyone should have to suffer so much pain in this day and age. However, not wishing to delay it any longer I did not do that.

I have written to my Consultant, and said how sorry I am for the system, and do not blame him, but the Health Board who need to do something drastic to get the lists down. He is a brilliant Surgeon, and I have been under him for many years, as he did my right knee replacement in 2011.

When we moved to Wales in 2001, the waiting lists for any surgery were minimal, but just what has happened in the last 15 years is a mystery to all, as they are the longest in the UK now. I did request that I could go to another hospital anywhere in the UK several times, but was told that the Welsh NHS would not foot the bill for that. In England as at today's date, the waiting time for a hip replacement from referral to treatment is 11-18 weeks maximum.

Patient D

In July 2016 I was seen by an orthopaedic consultant and was advised that I required a replacement left knee, I was told that I would have to wait approximately 50 weeks for this operation and I agreed to go on the waiting list.

I have other mobility issues including a replacement right hip, which was done in 1998, a left hip replacement which was carried out in 2011. Due to numerous complications, I underwent a complete revision of this hip in November 2013 and I also had a spinal decompression operation in in 2010.

When I saw the Consultant in June 2017 I was told that due to the 'clean ward' being closed for three months due to winter medical admissions, no joint replacement operations had been carried out during that period, resulting in the waiting time increasing to 90 weeks.

I saw the Consultant again in September 2017 and was advised that the waiting list had increased further to approximately 100 weeks, which means that it will be the summer of 2018 before I have my knee replacement – if I am lucky and the waiting list does not further increase!

This is extremely frustrating, not only for myself and my family but also for the Orthopaedic Consultants. It concerns me greatly that I am having to wait another two years for an operation and in that time my situation is only going to deteriorate further, meaning taking increased pain relief medication, which in turn impacts on my quality of life.

Presently I cannot walk any distance without the aid of two walking sticks and if I have to wait until the summer of 2018 then I can see me becoming housebound, which I know will have an impact on my mental health. I am 65 years old and although I do have arthritis, the extra pressure and pain I am putting my body through because of my left knee is causing further problems and issues with my mobility.

I would like to know what the NHS is planning to do in the future to help reduce the waiting list for replacement joint operations as this situation cannot be allowed to continue. I am concerned that the "clean ward" will again be closed to joint replacement surgery this

year, resulting in an even longer waiting list. The extra cost in medication for all these patients waiting up to two years for their operations must surely be eating into budgets.

Patient E

I had a right knee replacement in February 2015 with the understanding that the left knee would get done within a 2 year period once the right knee was successful and I was fully weight bearing.

The appointment for next knee never arrived and on pursuing this matter, I was added to the urgent list in April 2017. I was then told that there was no chance of surgery before Christmas as there was an 80 week wait despite being assessed as clinically urgent.

I am diabetic and can no longer exercise due to pain. My right knee has now failed and needs a full knee replacement. My muscles are wasting due to lack of movement. I have steroid injections but these are reduced in both efficacy and in time they last. I can't take pain killers due to stomach and bowel problems.

My life is on hold.

Patient F

Many thanks for talking to me about the time I have been waiting, I wasn't expecting a response in all honesty so thank you for taking the time to respond.

As mentioned previously I am quite frustrated by the time I have been waiting. I fully acknowledge that the NHS is very busy and it's challenging trying to manage expectations. My mum is a Nurse so I understand how busy it can be for the NHS.

I've had blood tests done by my GP all of which have returned negative. However I live a life of discomfort most days and I really could do with knowing what's causing it, I just find the waiting time to be very long. I'm still reasonably young at 38 and as I pointed out in my last message there are people with far worse conditions than I have so I can't imagine how they must be feeling having to wait but you can only do what you can I guess.

Patient G

At the beginning of 2017, my optician referred me for a CT scan after I experienced sight problems which were thought to be the result of a minor stroke.

I had a scan on 27th February 2017, and this showed a brain aneurysm that needed further investigation to decide what treatment would be best. I had another scan in March 2017 and it was decided to seek the opinion of a Consultant neuro-radiologist regarding treatment options.

I did not get to see the neuro-radiologist because two of the three neuro-radiologists had left and the other is on extended sick leave. I was told that a locum has been recruited in South Wales but will not be providing a service at my local hospital.

I have now been referred to a hospital in Liverpool but I am still waiting for a date for treatment. Since receiving the diagnosis, I have been extremely anxious in case the aneurysm should rupture. I have had on-going vision problems caused by the aneurysm and this had caused me to have several falls.

Patient H

My problems started just before Christmas 2016 when I got flu and then developed sinusitis and a chest infection, a clear, watery fluid

started to discharge from my nose. The discharge was constant and was accompanied by headaches and light headedness.

When the problem did not resolve, my GP telephoned the ENT Department and arranged an out-patients appointment. I didn't want to wait any longer so my GP gave me a letter to take to the hospital. Once there, I saw a doctor who examined my nose with a camera.

I was given a nasal spray to use and a follow up appointment. At the next appointment, I saw a consultant who arranged a CT scan. The results of the scan showed a crack in my skull from which the fluid was leaking.

I was told that I would have to undergo surgery but would need to have an MRI scan first. This took place on 7th April 2017. The surgery took place in June 2017, six months after I had the first symptoms. I am making progress but I'm still not fully recovered yet.

Although I cannot fault the care that I received from the doctors involved, I am frustrated about the time it had taken to get a diagnosis and the waiting time for treatment to remedy the problem.

During that time, I suffered from debilitating headaches and light-headedness and a constant stream of fluid from my nose which went down my throat during sleep and made me cough. I was off work since the symptoms started because I was feeling so unwell and I work with food so could not go back for hygiene reasons. I have lost a considerable amount in wages due to this delay.

Patient I

Hi, I have waited 70 weeks already and will be 88 weeks by the time they say I may be called for pre op for hip replacement surgery. My hip has deteriorated a lot whilst waiting and the last x-ray they look at now is 4 years old.

I was invited to go to Crewe for my operation (*107 miles away*) and when I rang them they said it would be another 3 months wait, so as it is such a long way for my family to travel I decided to wait the extra 6 weeks to have it done locally.

I now use a wheelchair to go out or two sticks. I'm fed up now. When I went to see the surgeon they were taking people from another hospital where the waiting list was even longer. I queried this and suggested that this meant we would then have to wait longer. This is not fair on any of us.

Patient J

My wife had to wait 16 months for a hip replacement operation. At first we were told that it she would have the surgery around Christmas time or perhaps the following February but, in fact, she had to wait more than a year before she actually had the surgery. While she was waiting for an appointment, no one kept us informed about the reason for the delays or about how much longer she might have to wait. Having finally had the operation, she now needs another procedure to drain away some fluid, which is gathering around the operation site. She has been waiting for this follow-up procedure for more than 9 months now and there is still no sign of an appointment.

She feels as though she has just been dumped. Her quality of life is not good and she often says that she wishes she hadn't had the hip replacement at all. She can't go anywhere where there might be large crowds of people because she can't risk being pushed or knocked. She is very unsteady on her feet and can't risk falling over. My wife is much less mobile than she was before and she can't do the things she used to.

She gets terrible pain and is very swollen and bruised where she had the surgery because of soft tissue damage. And she has just been left to suffer in this way for months on end. As I say, it feels as though she has just been dumped.

Patient K

I had had breast implants following a mastectomy as a result of breast cancer. I started suffering with terrible pain and some hardening in my breast. Initially I was told that the implant had ruptured and so I would need it replaced. However, I was later told that this was not the problem after all. Either way, I needed surgery to correct the problem. I had to wait 54 weeks for the surgery.

Throughout that whole time I only ever spoke to someone in the department and got updated if I chased them up myself. Nobody contacted me to let me know what was happening or how long it would be. I knew from the outset that there might be a “bit of a delay” but I had no idea just how long I would actually have to wait.

To begin with I was able to be quite patient about the wait. But then as time went on and no one contacted me I started to get concerned. I couldn't plan my life. I wanted to book a holiday but I couldn't because I was worried that I might miss my surgery slot. This was very stressful for my husband and my daughter.

While I was waiting the pain in my breast got worse and worse. I was worried about the possible reasons for the pain and why it might be getting worse. It meant I couldn't play with my grandchildren as I normally would because it was just too painful to lift them up or have them jump on me.

It made me angry. I felt it wasn't fair. I did get a call with an appointment within 12 months of my referral but then the slot was cancelled. To be honest, this just felt like lip-service. Like they had given me an appointment just to cancel it so that it looked like they were doing something. Maybe that wasn't the case but that's how it felt to me. I had the pre-op appointment but then the pre-op was out

of date before I was even given a date for surgery. When I asked about this I was just told "*Oh, it'll do*". I felt like I was being fobbed off all the time. Why would they bring me in for a pre-op if there was no chance of the surgery happening before the information was out of date?

By the time I saw the consultant I was really angry about it all and this affected the doctor/patient relationship. It's so unfair that there is a difference between the waiting times in England and Wales.

Patient L

I had to wait 2 years just to be assessed by a surgeon when I needed surgery on my rotator cuff. I had some calcification of my collar bone, which was restricting my movement so my GP referred me to see a physiotherapist. After 6 months the physiotherapist decided that I needed to have surgery so referred me on. When I finally did see the surgeon for a consultation he told me that I would be prioritised. However, I had to be taken off the waiting list while I went to see a cardiologist about a heart problem.

Once that was sorted, I was put back at the bottom of the waiting list and was told that I would have to wait another 12-18 months for the surgery. I wasn't kept informed about what was happening and I actually only found out that I was back at the bottom of the list because I contacted the department and asked. I waited for this surgery for 3 ½ years.

I'm retired now but I had been working for a supermarket. My employer was very supportive while I was trying to continue working but I was quite restricted in my ability to undertake any duties that involved lifting. It was clear from meetings with my managers that they were running out of patience so I decided to retire. My condition didn't force me into retirement but it was definitely a contributing factor in my decision to retire earlier than I had planned. My employer did try to support me but at the end of the day they're a

business not a charity and they couldn't carry me while I was unable to perform my duties fully.

I struggled with some of the basic necessities of life such as shopping. I can't carry any weight on my right-hand side. I used to enjoy playing golf but I can't do this anymore. I wasn't able to do small things that I would normally take for granted such as lifting up my grandchildren. I suffered with terrible pain and I had to take Ibuprofen at the highest dose possible. I'm not even totally sure that it is ok to take this alongside my heart medication but I had to have something to ease the pain while I was waiting for surgery.

Patient M

Hello, I believe you're looking for opinions about time spent on waiting lists.

I was referred by my GP to the hospital Rheumatology Department for checks a good two months or so ago, possibly longer. I was given a waiting time of 20 weeks which was unacceptable to me. I'm in constant pain every day, chronic pain. There are people out there in worse condition than myself but the waiting times are so poor for this service around here.

I am still waiting to be seen and have also been put on the cancellation list and no one has called me at all. The excuse I've been given is that no one wants to come and work for this Health Board. Hope this feedback goes some way towards helping.

Patient N

I never imagined the wait for a cataract removal could become so stressful. I waited nearly eighteen months in total before I was called for my cataract procedure. The last nine months became a real nightmare. I live in a fairly rural isolated location. I am also disabled with asthma and COPD consequently this means that I am unable to

walk very far without becoming very breathless, therefore this inhibits the use of public transport due the distance I would need to walk. I had to give up driving for the last six months due to my poor vision.

I went back to the optician as I knew both cataracts were getting worse especially the left eye, the optometrist confirmed that I had virtually become almost blind in the left eye due to the density of the cataract and confirmed that it would be unsafe for me to drive until the cataract removal and subsequently made a urgent referral but I still had to wait many months before I received the procedure.

I do not suffer from depressive personality, I always look on the bright side of life but I must admit the last six months of waiting became very trying. I could not go out in the garden if there was bright sunshine, indoors, the curtains and blinds needed to be drawn in whatever room I was in order to exclude bright light or sunshine. Simple things like watching the television became very uncomfortable. I had great difficulty in reading books or newspapers etc., I could not use my computer without great difficulty.

I managed to trip and fall in the house three times due to my poor vision, I must admit I began to feel really down as I had lost my independence and felt isolated and cut off from my normal daily activities. I became totally dependent on my husband which in turn impacted on his independence.

I cannot even begin to explain the difference when the cataract was eventually done. I was able to live my life again and regained my independence. I am a retired NHS nurse, I retired at the age of 65 so I have understanding of how things work but surely a cataract operation is a lot cheaper than a possible full hip replacement as a result of a fall which thankfully I did not suffer, but many do. Also if a cataract is left too long other complications such as blindness could occur.

And the sad thing - I am still waiting for the other one to be done!

Patient O

I started feeling pain in my left shoulder in early 2016. It was a pain I was familiar with as two years ago I had the same pain leading to an operation on my right shoulder. I visited my GP who prescribed Ibuprofen. This didn't help so I went back to my GP and he referred me to "walk in physio". This was extremely awkward as my work took me all over the country meaning I had to take time off work to undertake a six week course of physio. The physio didn't have any benefit so it was recommended I receive a cortisone injection.

Due to the pain I was in I decided to finish working away and look for work closer to home, in the hope this would make attending appointments a little easier. Unfortunately the pain was so bad the GP signed me off sick in July 2016.

I received a referral to the clinic in September 2016 where I was seen by a consultant and received a cortisone injection. This had no effect so I returned to my GP towards the end of September. In mid-October I was referred back to the clinic where I saw a consultant who referred me to hospital for a scan and maybe another injection. I received the scan in November 2016 which showed an arthritic shoulder which required an operation. I was put on a waiting list.

I feel if I had been given a scan first as last all the treatment in between which did nothing to relieve the pain, would not have been given. Saving the NHS money and me time. In March this year I saw a consultant who confirmed the diagnosis. I was contacted early December to see whether I was able to attend a pre-op appointment as the clinic had a cancellation. I attended this appointment where I was told I would be contacted very soon with a view to an operation in early January 2018.

I now have a date, for mid-January 2018. The length of time the process takes does cause financial issues. Sickness benefit is only given for one year, so I have been without financial support since July 2017.

Patient P

On 1st March 2017, I was placed on a waiting list to have a total knee replacement on my right leg. My next appointment was made for 5th October 2017. I was expecting the Consultant to tell me when I would have my operation. He told me not to go away on holiday during January and February 2018 as there might be an additional operating list at this time.

I normally spend these months abroad but cancelled my arrangements. I subsequently heard nothing and after many phone calls and letters was told that I was number 153 on the waiting list and they had no idea when my surgery would take place. I was told that I could expect to wait a further 92 weeks despite having been listed for 52 weeks already.

I have written to the Chief Executive and Chair of the Health Board with no response to date but was contacted by an administrator who has asked me to fill in a Freedom of information form before I can have information about the waiting list, how the recent funding announced by Welsh Government has affected the list and where I actually sits on the list.

I run my own business dealing in antique furniture and the pain I am suffering is making it hard for me to continue. I have had to alter my stance and gait to compensate for the pain and this is making my hip worse and affecting the other knee. I have to sleep with pillows under my knee to get any relief and I tend not to go out due to pain. My wife is also suffering as I am grumpy and have short patience due to this unremitting pain. Normally we would have been away over the winter and the sun and warmth offer some respite from the pain.

Having been told not to go away and missing this much anticipated break, we are both upset to realise that we have waited around for nothing. I am very disappointed with the NHS.

Patient Q

I had partial knee surgery in February 2015, this failed after 2 years and I was told it needed total replacement. I was advised that I would need to wait 80 weeks just for an appointment with the Consultant so I made arrangements to see him privately to move things forward and saw him in April 2017. He told me I needed an urgent operation but that thus was unlikely to be done before Christmas of 2017. In the meantime, I was waiting for an appointment with the pain clinic but this never came through.

I spoke to the Consultant on the phone in November 2017 and he informed me that he was due to have hand surgery and would not be able to carry out operations until at least after Christmas. He said I should be treated at the end of February or perhaps the beginning of March. In January 2018 I signed a form agreeing to be referred to another consultant. My predicted wait is now another 52 weeks minimum.

I used to be a very fit and useful member of society; refereeing rugby all over North Wales, organising and participating in politics and social schemes such as litter picks with Friends of Anglesey Coastal Path. I am an insulin dependent diabetic and it is essential that I stay fit and healthy which, with the knee pains and developing related ailments, such as sciatica, is proving very difficult.

The physiotherapy offered by the Health Board is ineffective as it is merely classes for general post-knee surgery with no individual time from the staff to deal "hands on" with an individual's case. I have now lost a significant amount of muscle tone in my thighs and lower legs which will affect my capacity to recover from further surgery.

I am unable to take normal pain medication such as NSAIDs because of the side effects. As mentioned earlier, I have never been given an appointment with a pain clinic.

My relationship with my family is severely affected as I am so grumpy all the time; dealing with the constant pain, having to get up at regular intervals and move around to avoid the legs getting stiff, the sciatica and increased back pain. I am unable to sit for long periods so that precludes going to the theatre or cinema, travelling far etc.

Patient R

I first told my parents that I had been struggling for some time with my gender identity when I was 15. My parents were very understanding and wanted to help but didn't really know how. They came with me to see my GP. My GP was very honest that they had never treated anyone in my position before and asked for a couple of days to discuss what to do with colleagues. I was then referred to Child and Adolescent Mental Health Services (CAMHS).

I had to wait a couple of months and then had an appointment. The person I spoke to also told me that they hadn't had any previous experience but had found out what to do next. I was referred to specialist services based in London, my first appointment was several months later.

I had a number of appointments over the next two years to discuss how I was feeling. This was helpful but did not lead to any action.

At my last appointment with them when I was approaching 18 I was told I would be transferred to the adult service and that this would mean a further wait.

Throughout all this time whilst I feel I have been listened to, it hasn't helped to get me the treatment I need. I have become increasingly frustrated and it has led to me losing confidence. I have found it impossible to concentrate on my education and it has affected my relationships.

I have found support from others in similar circumstances by joining online network sites. I know I'm not alone and in some ways this helps but it also confirms that there is little chance of any action any time soon.

Many people have resorted to ordering hormone treatment online and whilst I'm told this is not a safe option I can understand why people do it. There is a big difference in your body between 15 and 18 and with every month that passes without treatment I feel my body is going further away from who I am.

I am now suffering with anxiety and depression. My GP told me to see someone privately about this because the NHS doesn't understand.

I have been told by adult services that I will have to wait over a year for my first appointment.

Learning from what people told us

The stories shared with us illustrate what life is like for some people in Wales waiting for treatment. This includes the additional issues that can be caused when communication is poor and people feel it is up to them to coordinate the various elements of their care

These stories should be a powerful reminder to those responsible for planning and delivering NHS services of the harm that can be caused by inactivity.

In our current system the requirement to monitor, report and act on harm does not include this.

The number of stories in this report equate to only a fraction of the missed targets reported each month by the NHS in Wales.

For those who spoke to us this measure is unlikely to hold much meaning. Instead, most people measured their wait in terms of the impact on their day to day life, their finances, their relationships, their careers, education and their independence.

It is difficult to see how clear and long established targets on waiting times are, on their own, meaningful to anyone. As they stand, they are not providing assurance to the public nor driving sustained improvement.

Responses to the recent White Paper “Services fit for the future” indicate wide-spread support for the introduction in Wales of Duties of Quality and of Candour. This provides a meaningful opportunity to set out a more effective basis on which performance is judged.

Our recommendations

The Welsh Government should, in developing a framework for the introduction of duties of quality and candour:

- set out clearly and simply what quality means from a service users perspective
- recognise the harm done by inactivity as well as the benefits of timely care
- issue revised quality indicators
- require NHS bodies to monitor and report on quality in a more meaningful way including the harm caused by inactivity.

The Welsh Government should work together with NHS bodies in Wales to make sure their plans clearly set out how waiting times will be improved, and take appropriate action if improvements are not made.

NHS bodies should ensure:

- They communicate regularly and effectively with people who are waiting for treatment
- People waiting for treatment know who to contact if they have concerns or need support managing their condition.

Acknowledgements

We thank the people who took the time to tell us about their experiences. We hope they influence decision makers to make improvements so that other people's lives are not affected in the same way.

CHCs will continue to monitor referral to treatment times across Wales and provide constructive challenge where improvements are not being made.



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