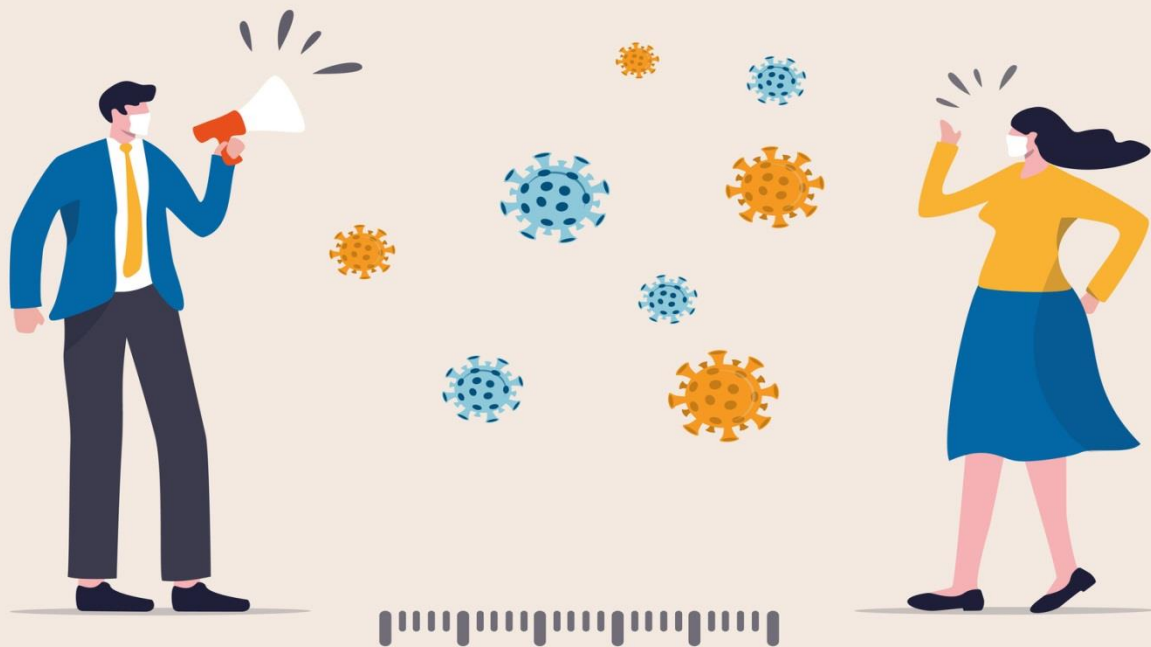


Living with coronavirus: health and care services during winter



Accessible formats

This report is also available in Welsh.

If you would like this publication in an alternative format and/or language, please contact us.

You can download it from our website or ask for a copy by contacting our office.

Contents

Introduction.....	4
What we did.....	5
What we heard.....	7
Summing up.....	35
Thanks.....	36
Feedback.....	36
Contact details	37

Introduction

Community Health Councils (CHC) are the independent watchdog of NHS services in Wales. We encourage and support people to have a voice in the design and delivery of NHS services.

CHCs seek to work with the NHS, inspection, and regulatory bodies. We provide an important link between those who plan and deliver NHS services in Wales, those who inspect and regulate it and those who use it.

CHCs hear from the public in many different ways. Before the coronavirus pandemic, CHCs regularly visited NHS services to hear from people while they were receiving care and treatment.

CHCs also heard from people at local community events, and through community representatives and groups.

Since the coronavirus pandemic, CHCs have focused on engaging with people in different ways.

This includes surveys, apps, video conferencing and social media to hear from people directly about their views and experiences of NHS services, as well as through community representatives and groups.

There are 7 CHCs in Wales; each one represents the “patient and public voice” in a different part of Wales.

What we did

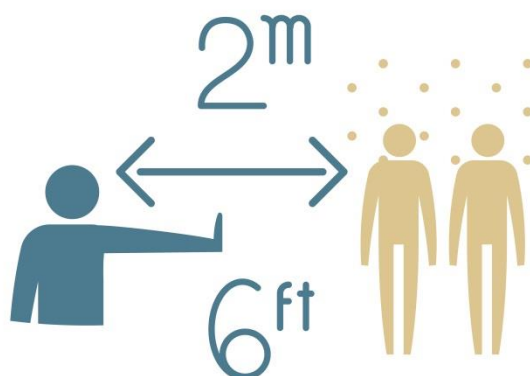
In a few short months, the coronavirus pandemic has changed how we live and how we work. Some of these changes may well remain with us for a long time.

The challenges we are facing together have reminded all of us in Wales how vital our local community networks, health and social care services and our wider voluntary and public services are.

With so much changing, and so quickly, it's important that health and care services know and understand what's working well and what might need to be done differently moving forward if they are to meet the needs of people living in Wales and respond to what matters to them.

Since we have been living with coronavirus, some of the ways people have been able to share feedback with CHCs about their views and experiences of NHS care is by completing our national and local surveys, or by contacting us via phone, email and website.

The feedback we receive through our on-line surveys is only one way in which CHCs hear from people locally about their NHS services.



CHCs also pick up feedback and issues in other ways, including:

- through our enquiries and complaints advocacy service
- engaging within local communities, through local community networks, community representatives and groups
- monitoring NHS plans and performance, including feedback and complaints
- information shared locally through social and other media.

We know that health and care services are working together to think about what they need to do to provide care and support during the winter, when things get even more challenging.

So during the first 3 weeks in August, we asked people across Wales to tell us what is important to them about their own health and care and the health and care of their loved ones in the winter months ahead. We asked them to do this using our survey, or by contacting us in writing, phone or social media.

We wanted to know so that health and care services can work together to make sure their plans to deliver services over the winter period respond to the things people are worried about and that matter most to them.

We heard from 350 people who responded directly to our survey.

Our report reflects what CHCs heard from people through the survey alongside what they heard through their day to day activities in local communities. Our report highlights the key things we have heard from people living in Wales**in their own words.**


What we heard

Peoples worries about their winter care

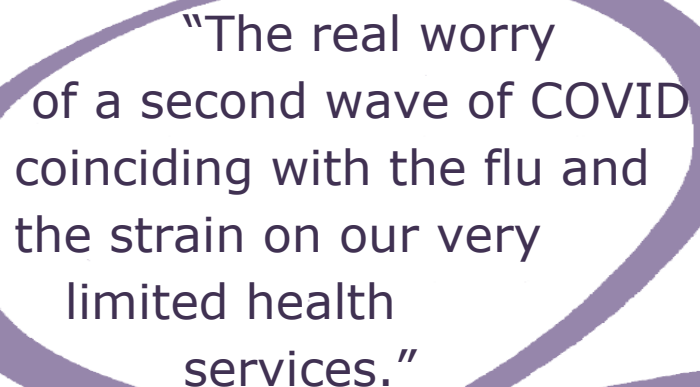
A second wave of COVID-19

Many people told us they worry about a second wave of COVID-19, and the impact this could have on people and health and care services during 'flu season'.

Some people think this could happen in their community because they are used to lots of people coming in and out of their local area.



"The influx of new students to our university towns alongside tourists."



"The real worry of a second wave of COVID coinciding with the flu and the strain on our very limited health services."

Others want to be sure that the test, track and trace system will be able to cope:

“Is there capacity to test the huge increase in those with symptoms especially as symptoms are associated with the usual winter illnesses we all have at this time.”

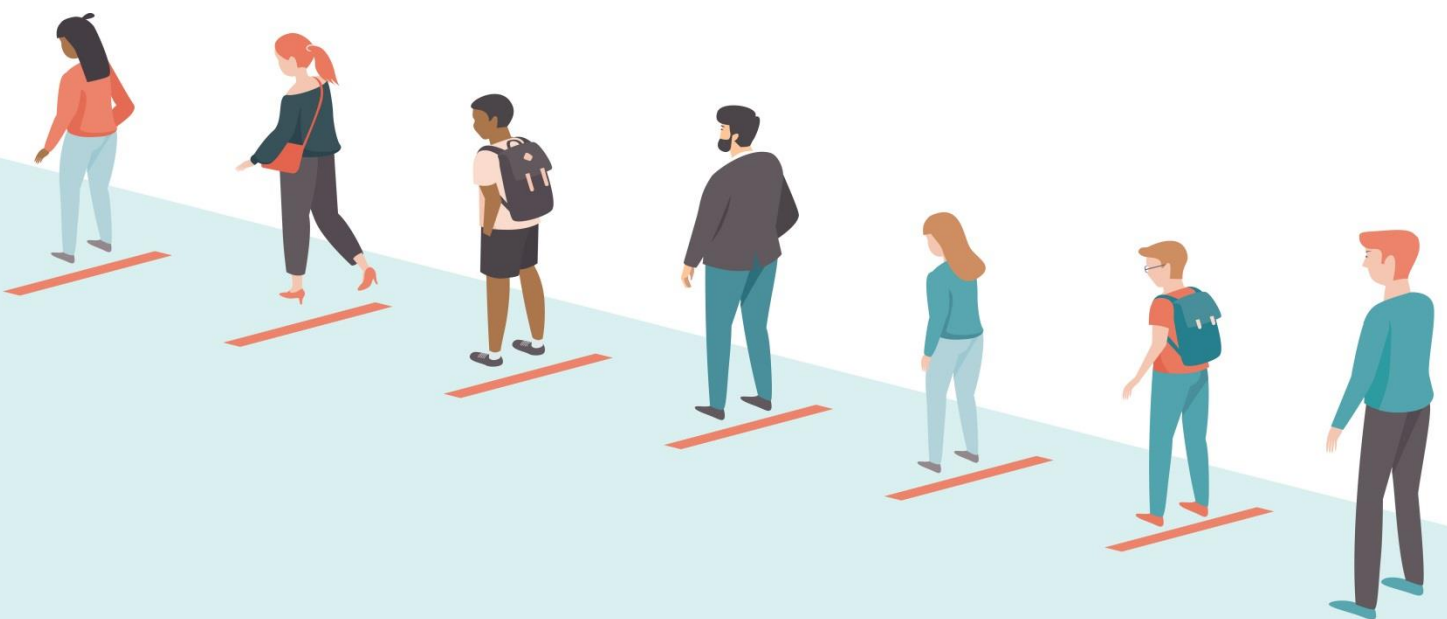


Catching COVID-19 & other illnesses

We heard from many people that they are worried about catching COVID-19 during the winter, at a time when there will be lots of other winter coughs and colds around.

Some people are concerned to make sure there is quick action and good information to people if there is a serious outbreak:

"That there will be enough information given out if there is another serious outbreak of covid 19 and also a quicker lockdown if there is."



Some people told us they are reluctant to attend for regular healthcare appointments or important treatments – even though this could affect their existing health conditions. This is because they are concerned about the safety of healthcare settings:

“I get frequent chest infections in the winter. It becomes difficult to breathe and have almost had to go to A&E on a few occasions. I usually receive a care package of steroids and antibiotics, which help after 2 - 3 days. I know that if I catch Covid in the winter that I will likely die.”

“I have had my treatment so far in Werndale for cancer. Now that my 6 weeks treatment is over, I need some more tests but I don't want to go to Glangwili, as I don't know what it will be like. Werndale was good, it felt like they had it all well controlled and I am less confident about going into a hospital in the winter when people will have coughs and colds. How can the staff keep me safe or make me feel safe - don't know what will reassure me. Maybe I just won't go but my wife tells me I have to go.”

Many people are worried that they are more likely to become ill over the winter. This is because they have not been receiving the usual level of checks or treatment for the conditions they are already living with, such as diabetes.

"I am asthmatic, no annual review this year, or even a phone call from asthma nurse to check, which is inexcusable

.....Husband has COPD & diabetes, no specialist reviews being offered by Ystwyth Surgery, which makes a mockery of the principle of prevention?"

"respiratory services for my chronic lung condition, that isn't cutting me short on my care. I have shielded for 5 months with poor specialist care and I don't think I'll make it through the winter without a hospital admission. I'm terrified."

We heard that people are concerned that if they feel unwell they won't know if their symptoms are COVID-19 or something else, like flu. Others are concerned that if they have a different illness this might be missed if people assume it is COVID-19:

"What if I have a winter cold/bug. How do I differentiate between this and Covid and will I need to isolate?"

"Coronavirus being blamed for every illness, and other illnesses being missed"

Some people told us they were worried about their children returning to school.



Some people we heard from had already caught coronavirus. We heard their worries about the long time it was taking to recover and not knowing about the longer term affects:

“Evidence from the Zoe app is that 1/10 are experiencing long term symptoms. We have nowhere to go in Wales for assessment or treatment.

This is exacerbated by many not having been hospitalised or even had a positive test. I was infected around 13 March and have not been able to access a test of any sort, or investigations past GP ordered blood tests.....

As more people are infected with covid, this will be something you will see more of and will need to plan for the care of individuals like us, and to understand the nature of this infection as one that can affect fit healthy individuals for far longer than the 14 days we have been told by the government”

Getting a flu vaccine

Lots of people told us how important it is that they can get a flu vaccine. Some people are concerned that there may not be enough vaccine to go around. Others worry that they may not be able to get the vaccine early enough or as easily as they usually do.

"I have 3 long-term health conditions (one is asthma, another chronic sinusitis, which are often exacerbated by the cold winter weather) so I receive a free flu jab. I am concerned about whether this will still be possible (in terms of time frame and available flu vaccine) in the event of a second wave this winter as well as the possibility of developing coronavirus"

"I am concerned about the flu vaccine. I qualify for the free vaccine due to my health conditions. Normally I attend a large community mass immunisation gathering and I am concerned about the safety of this given the coronavirus pandemic.

I am also concerned that there may not be enough vaccines to go around if demand increases because of the coronavirus pandemic. As a diabetic, I am also concerned, as I have not had any check-ups since the start of this year due to the coronavirus pandemic."

Keeping safe and well indoors and outside

Many people are worried that bad weather will keep them housebound, or increase their chances of falling over and hurting themselves. Some people worry about falling indoors, especially if they live alone.

"Falling in or outside the house, being housebound because of snow and poor road clearance."

"My worry is getting to the surgery, or to be honest, just out of the house during the winter months."

"Having pavements and roads safe to walk on in icy conditions"

"Like everybody, winter plays havoc with the bones, so it will staying in again. The cold weather and I don't suit..."

Some people told us about their difficulties in keeping their house warm and dry. Some worry about paying their heating bills, including if they are working from home:

"Damp house, cold, brexit, electricity bill"

"Rising cost of electricity during the winter as I only have electric heaters and draughty windows"

"Increased heating bills at home due to home working"

Lots of people told us they worry about care and support at home. Will carers be able to reach them or their loved ones? What about getting food and medication if they are isolated at home or if they have to travel and wait in the cold outside?

"My carer travels on public transport to get to me. She has only just started coming again after four to five months because they cut the bus service so much. Please put on enough buses for key workers in rural places. The service has been cut due to Covid"

"Worried about having to queue outside a pharmacy to collect a prescription in pouring rain or cold winds when I'm already running a temperature."

"Had no care or support since March. Not for physical or mental health. Supposed to be seen weekly. Terrified to face winter alone without help."

"As a widow living alone with my nearest family in Swansea, my concerns are for my care should I catch influenza or covid.eg shopping, eating & personal care."

"The senior citizens of my age and over.....88....must never ever have all of their support network taken away overnight again and be left to fend for themselves without thought of their homes being kept clean and hygienic, their laundry attended to and their complex medical care abandoned...."



Caring for and about others

We heard that many people were not worried for themselves. Instead, they were worried about the impact on those they care for if they or their loved ones became ill:

"I am concerned for my 88-year-old mother particularly with regards to her accessing medical care. Will home visits be available?"

I am also concerned about my husband, who is experiencing a resurgence of the symptoms with first onset 30th March - his initial bout of Coronavirus symptoms lasted 11 weeks and so far he has been quite poorly again for around 3.5 weeks.

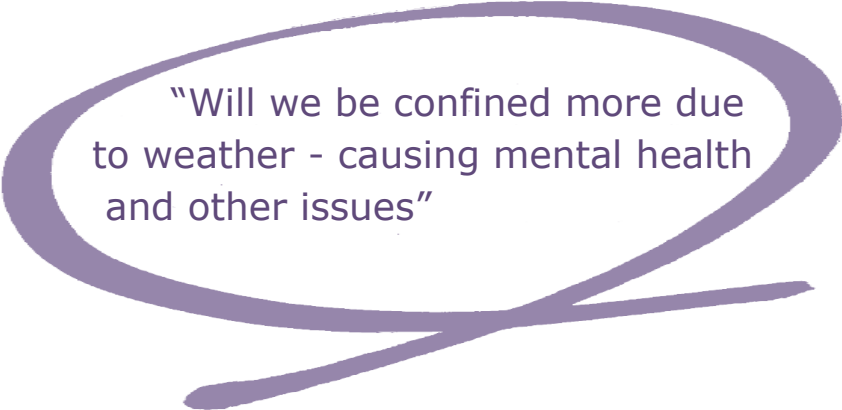
The NHS have been great, but limited support has been provided in the management of his illness at home as he was always discouraged from attending hospital and GP, for which we are thankful in many ways - but it would be nice if people had checked in about how we have been managing (not friends and family, but professionals), as we have a 5 year old to care for too."

"Inability to receive respite care for the person I care for in an emergency will the care workers out in the community revert to their normal visits."


"My general health has deteriorated over the last year (blood pressure and respiratory problems), so I'm very worried about continuing Covid-19 and also about flu. Also, my mother, who lives in England, depends on me increasingly because she is losing her sight and has other health issues."

Mental health and wellbeing

Lots of people shared their views about the impact of the COVID-19 restrictions on their mental health and well-being, as well as those around them.

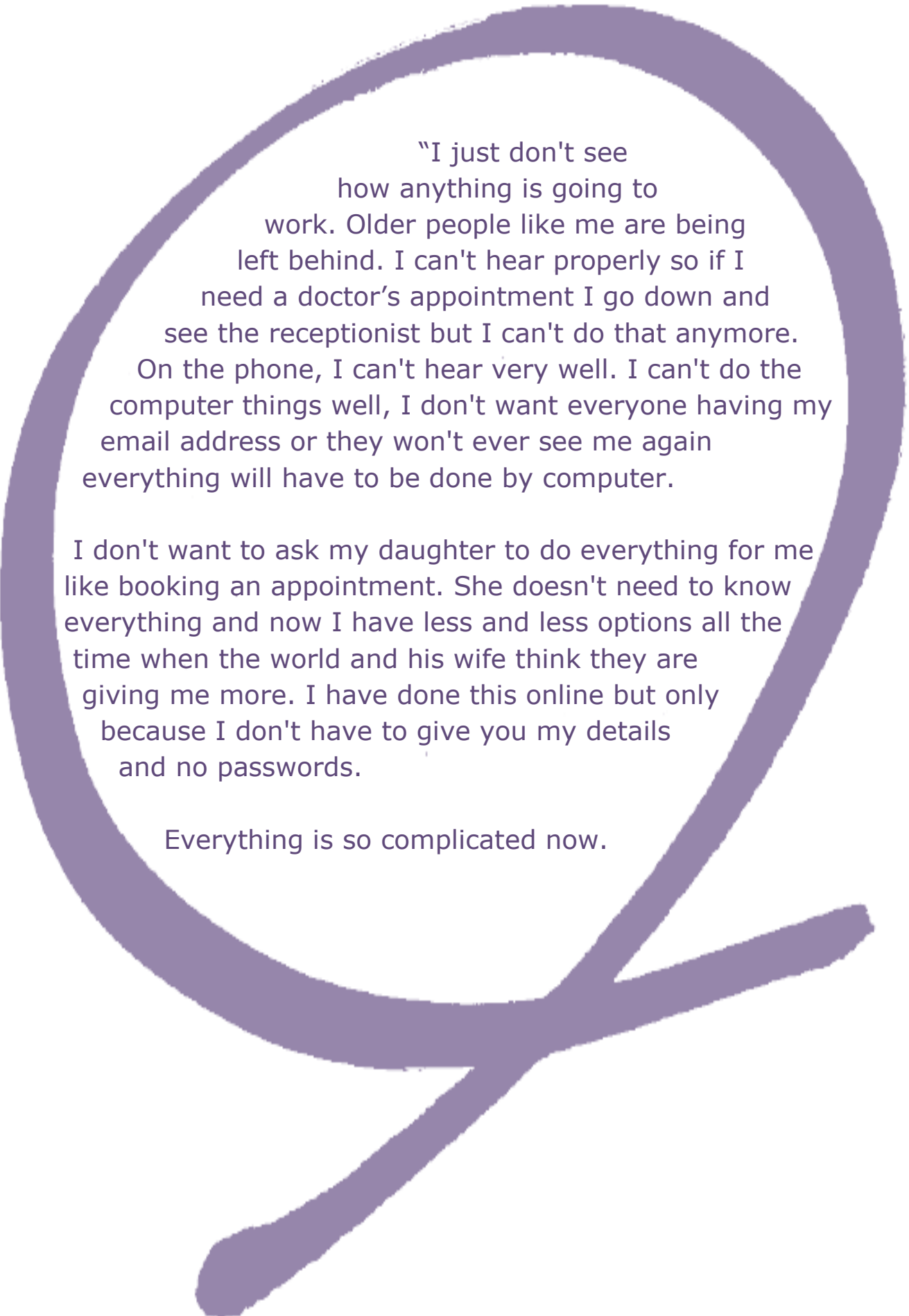


"Will we be confined more due to weather - causing mental health and other issues"



"Day services for learning disabilities haven't yet reopened and may not until next year. This isolation will affect the mental health of my son and be exhausting and stressful time for parent carers"

For those who have already spent a lot of time shielding, feeling lonely and being isolated over the winter is a big worry. We heard concerns that communal areas in sheltered housing will remain closed. One older person shared their fears about being left behind, having to depend on others, and losing face to face contact:



"I just don't see how anything is going to work. Older people like me are being left behind. I can't hear properly so if I need a doctor's appointment I go down and see the receptionist but I can't do that anymore. On the phone, I can't hear very well. I can't do the computer things well, I don't want everyone having my email address or they won't ever see me again everything will have to be done by computer.

I don't want to ask my daughter to do everything for me like booking an appointment. She doesn't need to know everything and now I have less and less options all the time when the world and his wife think they are giving me more. I have done this online but only because I don't have to give you my details and no passwords.

Everything is so complicated now.

Some people shared their concerns about the availability of public or community transport, or the safety of other forms of transport like taxis. This limits their options and ability to live independently. Others worry that community and social groups may be affected:

"I worry how I will get about as I don't drive and taxis are not safe, nobody wears PPE and taxis are not disinfected"

"Getting into work during the winter as I can't drive.... getting public transport during the pandemic."

"Social isolation if small community/social groups are unable to run due to Covid"

We heard concerns from one community that there would be an increase in domestic violence when people are having to stay inside more because of COVID-19:

"Although we think our area is not significantly affected by domestic violence we are concerned about the increased number of hidden cases that will rise to the surface when lockdown eases more".



Being off work

People told us their fears about being off work. This included being off work because of a requirement to self isolate. It may be because of the economic situation leading to redundancies. It may be because people are off work due to illness waiting for treatment.

"...resurgence of symptoms...son caught it too and had it for around 10 days – 2 weeks (and again very limited support to check all was now well, etc).

I feel I have been expected to just cope alone (no family locally) and muddle through even when one of my employers (I have 2 part time jobs and am a masters student) said I was "choosing" to stringently distance from work...

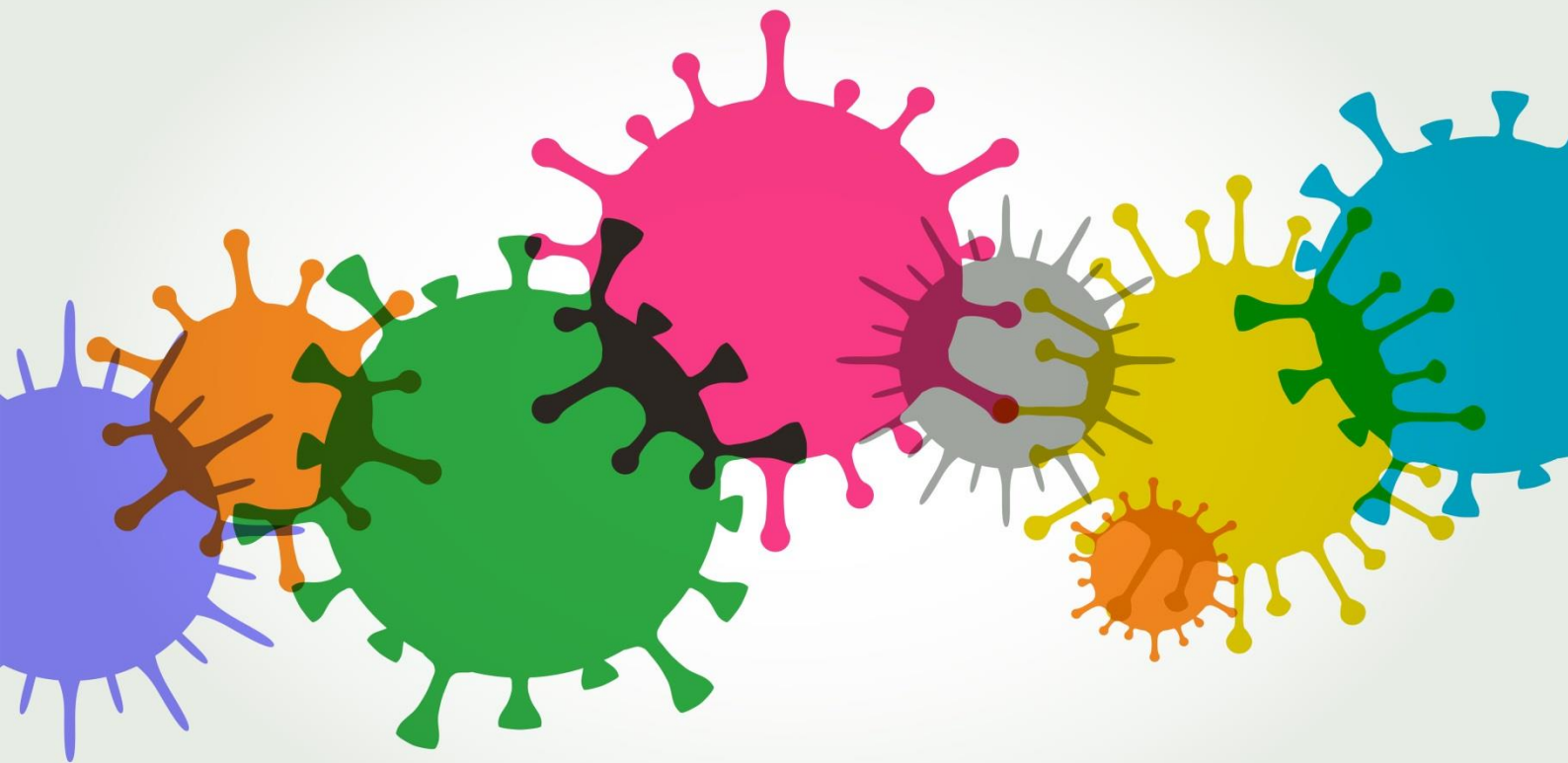
I don't feel this was a choice, having seen first hand the impact of the virus and feel my GP should have provided me with proper evidence for my employer.

I just used the self-isolation on 111 in the end on the advice of employer who paid me just two lots of ssp over the 4 months
I stayed away.....

"How will it affect my job?"

"....Work related worries such as multiple absences due to self-isolating or possible redundancies"

"I had a hip replacement beginning of this year and was due another 12/14 weeks later. Due to COVID I'm still waiting. I am very concerned about this I have been on sick from work for a year already. I need to get this sorted before another break out and the usual winter illnesses.



Being able to get the care I need when and where I need it

Most of all, people told us about their concerns that an already stretched health and care system won't be able to cope with increased demands over the winter period.

People are concerned they won't be able to get the care they need when they need it. People are concerned about what effect this will have on how they live their lives, and what this means for their future.

For many people, they are worried about being able to see a GP when they feel unwell. Some people think this will be easier if they can continue to have their appointments by telephone or videoconference.

Others worry that the systems in place to find out what's wrong act as a barrier to seeing a healthcare professional, and doesn't meet their individual needs.

Some people told us they needed face to face appointments. This is because they didn't or couldn't use online and videoconference facilities, and telephone is not always suitable.

Some people told us they didn't want to bother their GP with things because they don't seem serious enough when the service is stretched.

"Get timely appointments. I am more than happy for them to be virtual as it is a whole lot more convenient and should be quicker"

"I'm also worried about other things - like I feel embarrassed to bother the doctor with my knee pain because it doesn't seem serious enough"

"A friend of mine...aged 71 had severe pain in leg for many weeks. After a bit of 'persuading' he phoned GP practice. Receptionist asked if he was online and told him website where he should fill in details. After completing he was informed he should phone 111 or contact GP but info would not be passed to GP.

He felt exasperated as that was what he tried to do in the first place. After 2nd call to practice he was phoned back by GP and prescription issued.

The point is many elderly may have given up and a better system needs to be implemented".

"Accessibility access in regards to GP as I am deaf and find it hard to deal with some people on the phone, would love text/email access"

"Accessibility. Everything is so telephone centric. People need alternative means to contact doctors, including email and text. It is not okay to have to tell the receptionist detail of your health problem.....

I have a relative with dementia, who doesn't remember what he is told on the phone plus doesn't give the doctors an accurate picture.

Usually I attend appointments with him. There is no mechanism for my input into this process since I don't hear.

We heard that getting to see other health and care services in the community and through home visits is also important. Some people are struggling with this.

“How can I be sure that there will be a doctor available to visit patients at home when needed.”

“Face to face, access to GP, dentist and other healthcare providers”.

Being able to access healthcare via GP/mental health team/social services. Currently impossible as all locked away behind locked doors

Lots of people told us it's important to them to stay healthy and that routine, NHS funded healthcare services are available to help them do this. They worry about being able to get regular health and screening checks, and to identify problems or respond to issues at an early stage.

They worry about an already big backlog of routine checks getting bigger.

“That I will not be able to access routine care at my community mental health team if there is a second peak of COVID 19”

“Screening....and checks for cancers”

“That usual health care services are not working through the already huge backlog and winter illnesses will have an even greater impact on this”

"Would prefer to access primary services at the surgery instead of having to fund services myself, eg., ear syringing on a regular basis as apparently the surgery does not have to provide this service. Very unfair for those who wear hearing aids which are known to increase the wax in ears".

We heard from lots of people about their concerns that it would continue to be harder for them living with on-going conditions like diabetes because regular medication checks and on-going treatment or follow up had been delayed or cancelled.

"Lack of access to healthcare for myself and 93 year old mother. All calls she makes to GP result in nothing. Can't see GP. Can't see foot lady to cut awful toenails. Can't get blood pressure test at surgery (high no., since she has 18 multiple meds. Medicines review overdue 25 March 2020. They don't want to know regarding mums care.

Myself cancer tumour removed August 2019. Clinic at RGH cancelling routine cancer check appointments. Not happy.....Said they'd be checking regularly to ensure no recurrence of CANCER now seems that if you are over 50 NHS treatment is on hold.....

...told that high platelet blood result in April could not be investigated until Covid over.....understand Covid is terrible but other patients have health needs too and seems that over 50s are being abandoned".

We also heard the concerns of people who were waiting for a diagnosis before lockdown. We heard from people who had received a diagnosis but were waiting for treatment. We heard worries about delays when treatment has started but then cancelled or delayed.

"Due to covid19,
my elderly husband has not been
seen and desperately needs a hip
replacement. His mobility has deteriorated
considerably and he's in a lot of pain.

I don't see that he is now going to get seen this year
and it's heart breaking to witness the deterioration and
stress this causes. My worry is getting him to the surgery,
or to be honest, just out of the house during the winter months.

I so wish he could have been seen by orthopaedics! I totally
understand the situation with Covid, but what have
orthopaedics, ENT, cardiology etc. been doing? Staff,
consultants?

I just so wish he, and I know, so many others
could have been seen. I work for the NHS
and I'm considering leaving because now,
he needs more help- it's really sad.

So many people will die not
OF Covid but because
of it."

“My dad is currently receiving cancer care – some of his follow up appointments have been delayed by up to 2 months. I believe there should be plans made for every health board to have a clean hospital where cancer care can continue this winter with no delays”



"GP thinks that I might have late onset asthma, just worried how it's going to be managed over the winter months especially.

Doctor's surgeries not back to full operation, eg., for lung tests that I need, etc.....also to be able to have my appointment with the respiratory consultant...I have had a referral for, but they are not seeing outpatients at the moment.

And also how safe will it be for me if there's another wave of Covid".

"I am concerned about the increasing waiting times to access hospital services during the pandemic, especially services where timely treatment affects the outcome.

This is particularly important for cancer services".

Many people are concerned that mental health services will not be able to cope with increasing demand because of the impact of COVID-19:

"The current lockdown has had an impact on the mental health of the population and as it continues we have concerns that the level of people with mental health needs will increase, which will put further pressures on what is an already poorly performing service..."

Lots of people worry about getting to health and care services during the winter. People are concerned that transport and other community transport will not be available when they need to get to appointments.

People in rural areas worry about the distance they may need to travel, particularly for urgent care services.

Some people worry about the ability of the Welsh Ambulance Services to cope with the demand.

“My main worry is transport now we no longer can use the car.....transport to hospital outpatient appointment once they are started again, we used to use a car but can no longer drive and public transport is not possible for two disabled people needing wheelchair”

“Any hospital care required is a great distance from the village”

“WAST being overwhelmed”

“Access to GP our local surgery was closed and we were required to go from Llanbradach to Abertridwr this will be a bad journey in winter”

What people told us will help them stay well this winter

We asked people to let us know the kind of care or help they felt would help them stay well this winter. People shared their ideas for the things that would make a big difference to them – things that the health and care planners need to think about together.

For most people, we heard that if health and care services dealt with the things they had told us mattered to them, this would help them stay well.

People also told us about some other things that were important to them.

Throughout the pandemic, CHCs have heard every day how grateful people are to health and care workers and other key workers for everything they have done and continue to do.

They value the commitment and dedication health and care workers have shown to keep people safe and well and to care for them if they need support or are unwell.

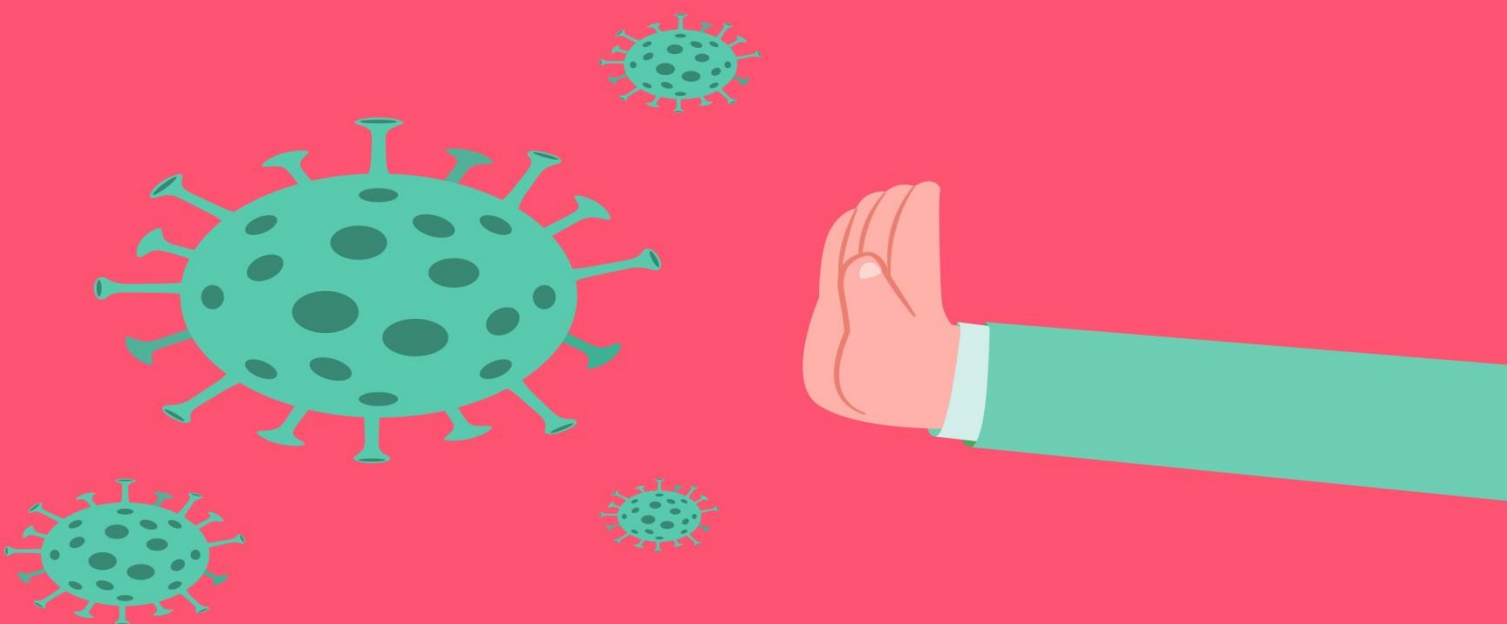
People have told us how important it is that everyone involved in providing health and care services, including the NHS, care and voluntary sectors are themselves well supported over the winter:

“Do all that we can to support those voluntary bodies who’ve been quite superb during this period of Covid-19. Also, in whatever setting, respect our wonderful care/health sector workforce”

People also shared their own thoughts and ideas. Some of the things people told us about are already happening and people think they need to continue. The things people shared included:

- clear, easy to find and simple public health advice and information on how to keep healthy (physically and mentally) and safe during winter, including eating well and exercising
- being clear about what people need to do to reduce the risk of infection in public. This includes the use of face coverings, and making sure people know, understand and follow the requirements (including people travelling into Wales)
- creative thinking to design services in a way that keep both COVID and non-COVID services running
- organising community based social activities in spacious venues and where everyone can socially distance
- providing virtual support groups
- introducing/continuing regular human contact by 'checking in' or 'keep in touch' arrangements for people who may be living alone or self-isolating
- providing local residential homes and avoiding out of county care
- providing easy access to counselling services
- keeping people regularly updated on their care and treatment and what to do if they need advice and support, including if they are waiting for treatment
- making sure health and care services use a range of approaches to meet people's individual needs

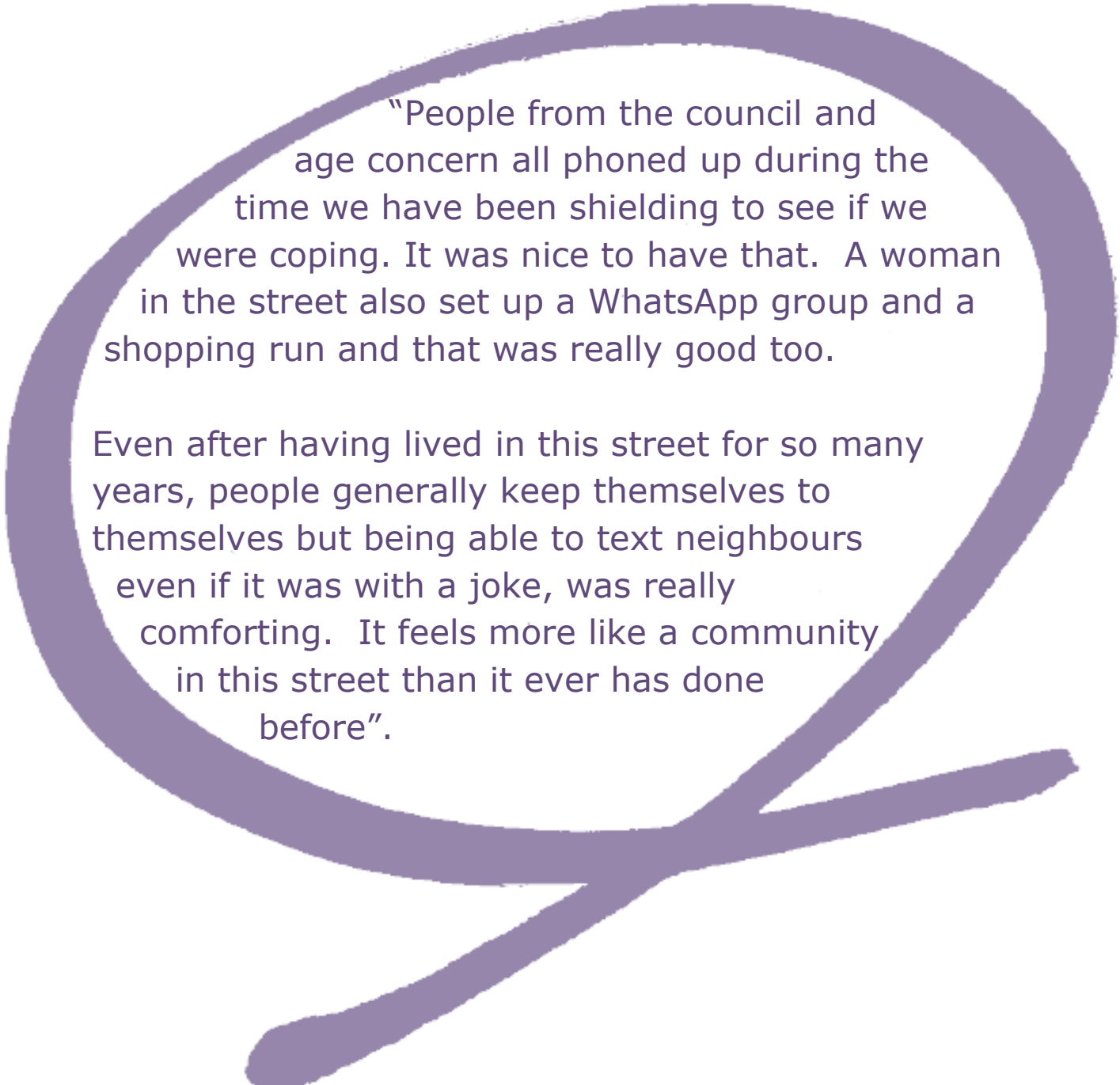
- continuing the option of phone and video consultations for NHS appointments
- continuing with delivery arrangements for food and regular medication
- easy access to local COVID-19 tests
- better connected health and social care services
- financial help to keep homes warm and dry
- a 'helpline' and community helpers/advisors to help people get the services they need when they need them
- drop-in assessment centres with facilities in one place so people can be diagnosed quickly
- clear plan rather than reactive actions to see it all through
- making sure there is clear, co-ordinated action between the NHS and local councils when we have a vaccine for COVID-19.



Summing up

What CHCs have heard from people across Wales shows very clearly just how much everyone's lives have been, and continue to be affected because of this worldwide public health emergency.

What it has also shown is how much we value and care about each other and our health and care services, and the importance of local communities in our everyday lives:



"People from the council and age concern all phoned up during the time we have been shielding to see if we were coping. It was nice to have that. A woman in the street also set up a WhatsApp group and a shopping run and that was really good too.

Even after having lived in this street for so many years, people generally keep themselves to themselves but being able to text neighbours even if it was with a joke, was really comforting. It feels more like a community in this street than it ever has done before".

Health and care leaders are thinking about what they need to do and how they need to organise services to meet the challenges we face during the winter period.

As they do, it is vital they think about and take action in response to the things people living in Wales have shared about what matters most about their health and care services – and that they clearly show people how they are doing this.

CHCs will continue to work hard in their local communities to help make sure the NHS continually listens and responds to the things that matter to people locally. The Board of CHCs will do the same at a national level.

Thanks

We thank everyone who took the time to tell us what matters to them about their health and care services in these challenging times. We thank you for sharing your ideas and suggestions about how things might work during the winter period ahead.

We hope they influence health and care services to recognise and value what they are doing well – and take action where they need to so that the things that cause very real difficulties for people needing health and care services are made better as quickly as possible.

Feedback

We'd love to hear what you think about this publication, and any suggestions about how we could have improved it, so we can use this to make our future work better.

Contact details



Board of Community Health Councils in
Wales
33 / 35 Cathedral Road
Cardiff
CF11 9HB



02920 235 558



enquiries@waleschc.org.uk



www.communityhealthcouncils.org.uk



@CHC_Wales