healthwatch West Sussex

YOUR HEALTH AND CARE INSIGHT INTO ACTION #3

Insight gathered
25 April – 08 May 2020

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At a glance

We have …

- Created dedicated Coronavirus information and advice on our website (adding a new page so the information is more accessible) and updated our FAQs
- We've taken part in virtual group meetings to hear peoples' accounts and are keen to join more of these groups.
- Received comments and stories about **positive ways services and staff are adapting, dentists, community services** and about peoples' experience of **COVID-19 Testing Services.**
- Shared and raised issues specifically around:
    - Continued confusion over shielding and social isolation
    - Access to dental treatment
    - Transport for pregnant women
- This report is being shared widely and with local NHS, Local Government and Community and Voluntary services, so they can hear where things are working well and help them identify any gaps.

Background

The way health, social care and community support operates continues to be affected by Coronavirus (COVID 19), but for the organisations offering this type of support the focus is moving towards restoring services. As more services are made available again, we can expect to see that they look different, as they will need to practice social distancing.

Healthwatch has been sharing some good examples of videos that have been made that explain and demonstrate the changes, which help people to know what to expect, which in turn offers some assurance of safety. With a fast-moving response to COVID 19, real-time intelligence for services about the issues the public face is so important, and we are continuing to work with partners on how we can make sure we hear things quickly.

West Sussex Health and Wellbeing Board

Healthwatch are members of the West Sussex Health and Wellbeing Board. All of our insight is shared with the board.

Read the West Sussex Health and Wellbeing Board's COVID-19 statement here, reassuring our local population that Board members, our systems leaders, are working together tirelessly to make the most effective use of our combined resources, to protect and support our residents and communities during these challenging times.

Amanda Jupp Health & Wellbeing Board Chair & Anna Raleigh Director of Public Health

As well as asking local voluntary and community groups (including local COVID 19 response groups) to help be our eyes and ears to hear peoples' experiences of health and care service at this time, we are introducing an operational weekly meeting with voluntary organisations that cover the whole of West Sussex, so together we can identify what is currently affecting our residents.

We continue to build strong and sustainable relationships with community support groups and those we need to influence. This includes developing new initiatives and opportunities for working together to understand and improve the support available to people.

We recognise across our health and care system that individuals and organisations are working flat-out to support residents. Strategically, we have observed some truly fantastic information and practical sharing amongst our community partners, and within the NHS, along with innovation and prompt/positive solutions.

In this weeks Integrated Care System briefing, Adam Doyle, Gold Commander for the Sussex NHS Response explained ***'that a lot of work is taking place to maintain and restore services that ensure our populations are getting the high quality care they need. As part of this, it is essential that we continue to listen and learn from people's experiences of using services – both positive and negative – which will enable us to improve areas where we could do better and to build on areas that are working well. We are, therefore, encouraging people to continue to give their views and feedback so we can all work together to make sure local people are getting the best possible care.'***

Where is our insight coming from?

At present, our opportunity to directly engage with West Sussex residents is more limited than before the pandemic.

We have redirected resource to be even more active on social media, sharing information and asking for feedback on health and care services. In these two weeks, our posts have reached 6,091 people directly (up by over 60% from previous fortnight) and been seen in many local community group pages.

We also continue to actively seek insight about health and social care experiences through our website, newsletters, responding to calls and emails via our Helpdesk Team, and virtual events such as group coffee meetings.

Community and Voluntary organisations are playing an even bigger role in being our partners to be *eyes and ears* so we can understand the experiences of those they support. To ensure that we can make quick and effective use of what they share, we have introduced a weekly meeting for West Sussex voluntary partners. If your organisation isn't already involved and would like to join these meetings to share insight from your clients/members/communities, please do contact us.
This report is a collation of all these sources of insight.

Advice and Information

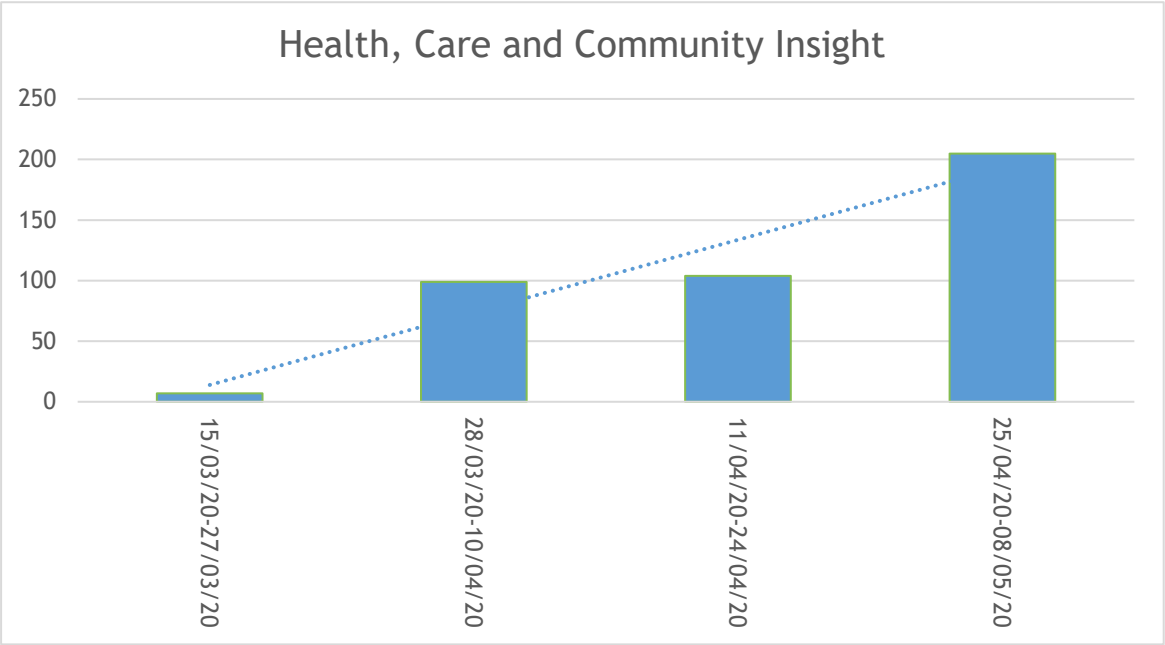
Since the Coronavirus outbreak, we have had a greater focus on our information, advice and signposting service, to help people get the information they need from a trusted source.

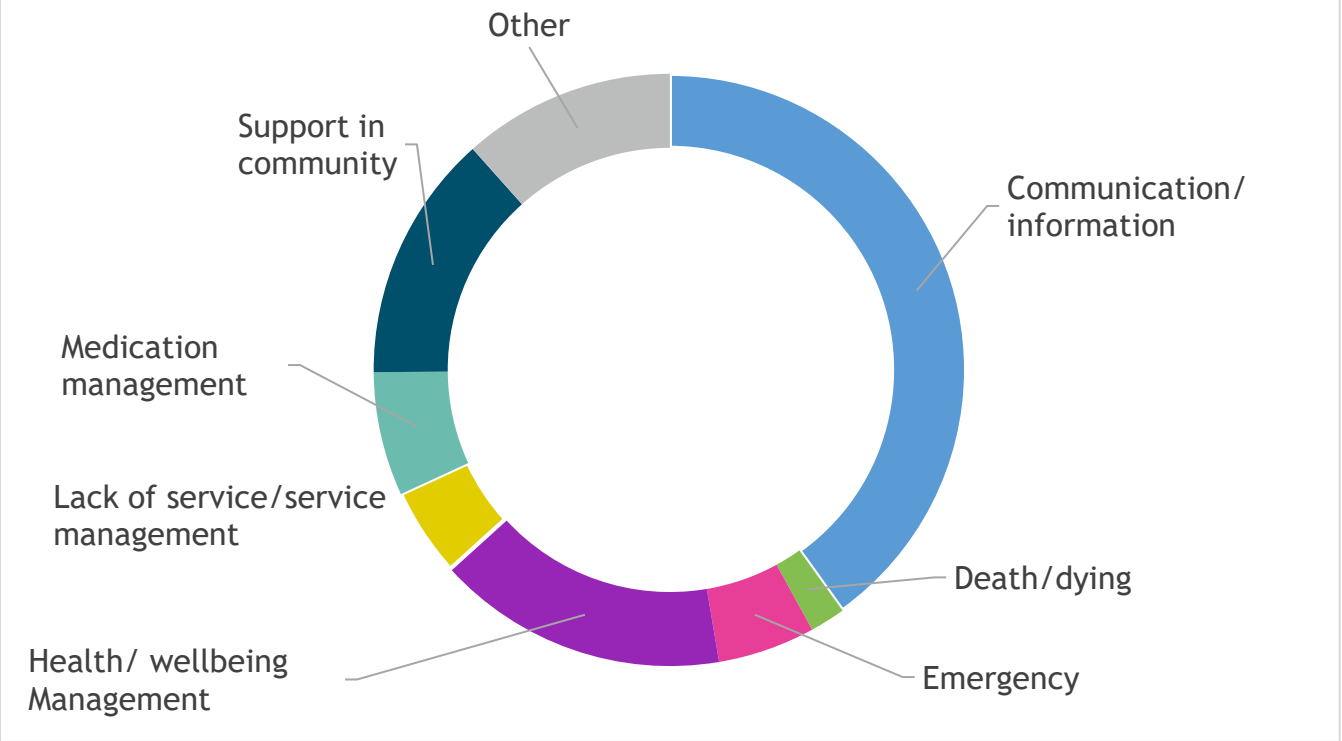
We continue to provide briefings and new information via our dedicated Coronavirus advice and information page. During this fortnight we have attracted **544 new** web users (of which over 32% were as a result of social media posts). We have also posted information on social media where we see potential confusion (as exampled on page 6.)

We update our Frequently Asked Health & Care Questions Answered working with stakeholders and based on what we are asked by the public and community and voluntary sector partners.

What are we hearing?

This graph shows the level of insight we are hearing fortnightly. We are also seeing peoples' needs changing and services responding and adapting.





Communication and information

What's working well?

Individuals and organisations are sharing with us how they are working, communicating and sharing information. The following examples helped us flag concerns to other parts of the system.

"I'm a councillor and am managing to see most of my clients online or by phone. Some have decided to wait until we can physically face-to-face again. This does worry me as the reasoning isn't always clear. Some people seem to think they mustn't make any demands at this time as other people are worse off and need services more. This could be quite detrimental. I'm trying to stay in touch, and make sure that they know it is ok to need and seek help.

Lady called Dentist for support with her broken tooth and was told to visit her local pharmacy and ask for some dental adhesive to fix her broken tooth. On arrival at the pharmacy she asked for the adhesive and the person who served her asked if she had a broken crown the lady informed the assistant she did not have a crown, the assistant who has dental knowledge could see from a distance the crown prep and informed the patient she had a broken crown and provided the correct adhesive to stick the crown back on.

We have shared this with the Sussex Dental Committee to investigate whether video triage may be able to help in this type of circumstance."

Local people continue to respond to requests for **mutual aid and information via social media.** In some cases, we can see the advice coming forward is appropriate and in other cases is misdirecting people. Where we see this, we post a formal response with information and advice.

For example: A lady posted on Facebook asking for advice on how to remove a ring from a swollen finger. There were many responses, but this exchange was interesting. The lady had been advised by a commentator to phone the fire brigade: "*Thanks everybody I will give the fire Brigade a call in the morning*". We responded saying to ring your GP in the morning. Advising, in the meantime if it hurts or swells more don't feel like you shouldn't call 111 about this, the NHS is still there to help with A & E, or not. It's virtually empty at the moment with hardly any accidents due to lockdown.

The response back was "*Thanks. I just don't feel it's something I should be bothering any of the wonderful NHS with at the moment. Let's hope the swelling goes down. I got a rose thorn in it a week ago which is the cause.*" We carried on the conversation to say definitely don't leave it... sharing also some feedback on local GP service: *I've had a video appointment with my GP this week, they are still dealing with non-COVID patients, they've been great.*". Others also responded to suggest they do not leave it and go to A&E, and the risk and speed of sepsis.

What's confusing people?

People continue to tell us they are **struggling to understand *Isolating* and *Shielding***, with some reporting confusion around text messages received from GP.

Others have experienced, for example one resident waiting 7 weeks' after registering online, and through a Haematology Support Group known some people have received a text message, and other have received neither.

> My mum is not eligible for shielding and the extra support with supermarket slots, despite being elderly (90), asthmatic, diabetic with a heart condition and breathing difficulties. She has steroids and antibiotics several times a year for severe chest infections. I tried to register her through the Extremely Vulnerable adult form. This triggered a "*holding*" response and eventually a letter from her GP stating she did not fall into the strict criteria for shielding, but the GP did feel she was high risk and therefore needed to strictly follow social distancing advice. However, my brother received a letter this week (end of April) telling him he was high risk and needed to shield for 12 weeks from the date of the letter. He is asthmatic, and approximately two years ago had pneumonia. However, other than this, he is fit and well. However, he lives in Cornwall and my mum lives in West Sussex. Are different counties using different criteria? Are there targets to be met? By no stretch of the imagination is he more vulnerable than our mother. It doesn't make sense!

Text message received stating the recipient's status had been reassessed as "Moderate Risk" rather than "High Risk". The message also included clickable links to advice and community support. The person was concerned it was a scam and responses showed a wariness to the message, with people advising the person to ignore it.

Post later showed the message was from the GP Surgery and others had also received same message. Once clarified as genuine, the recipient and commentators stated their confusion over what "Moderate Risk" meant, why they were classed as it and what they should do. People commented that they had searched the term and found limited information. The message caused anxiety and confusion.

In addition, people were unsure which member of the household it was referring to, and others had previously received shielding information and now had this message.

Our actions:

- We've put forward suggestions to the West Sussex Clinical Commissioning Group on potential wording and alternatives ways to help people to stay safe.
- Community partners and supermarkets are working to support those self-isolating and you can find information on how to get support in our FAQs. FAQs also explain how to cancel food parcels if you are receiving them but don't need them.

Support in the community

What's working well?

It is clear that voluntary and community organisations and groups, as well some private providers we have heard from have adapted their services to continue to be able to support residents. We've showcased some of the different ways people are also supporting others, via our social media. Here are just some examples.

Youth Support Service Provider: Most staff are on furlough sadly, but we have been experimenting with virtual youth club offers. We have also set up a route to online counselling for mental health support with partners and identifying what training staff need to make sure that we operate a safe environment online.

Voluntary Action Arun & Chichester

Arun & Chichester Voluntary Action are providing food parcels weekly with goods given by *UK Harvest*, as well as providing free children's resources, chocolates, coffee and paperbacks...all donated. We have also set up a neighbour's scheme where people get in touch to volunteer or with a need. Mainly it has been shopping and prescription collection. Our church pastoral team have been working hard to stay in touch with those who are socially isolated, especially those without the Internet. Our vicar is putting out a message every day online.

Cruse Bereavement Care have curated resources specifically on grief and bereavement during the COVID 19 outbreak and commissioners have provided more funding so they can offer more support to local people.

Parent Carers Forum: All of our staff and volunteers are working from home, but we are still providing a full service (and more) for our Parent Carers and their families at this challenging time.

Our website is constantly being updated with relevant and up to date information and resources from how to help our parent carers to support their children with lessons at home, different behaviour and challenges that this change in routine has brough about to how to access medical care. We can help with Care, Education, Health and Wellbeing or be the listening ear if someone needs to *'just talk or unload'*. …

We are hosting Virtual Pop-Up events Via Zoom every Tuesday and Thursday at 11am for an hour, which parent carers and their children can participate in, they can ask questions, discuss things important to them with other parents and staff/volunteers or just listen. Each Thursday Pop-up we aim to have a special guest, last week we had Luke from The Springboard Project talk about their organisation and answering questions, this week we have Marie of Amaze Compass Card joining us. These virtual Pop-Ups are proving to be very popular as our parent carers don't have to leave home to feel supported and included and we may continue these into the future. Covid-19 has really made us as an organisation rise to the challenge to support our parent/carers and think differently about how we do things.

Support in a Changing World - Learning Disabilities

The Aldingbourne Trust continue to provide daily support for everyone in their Supported Living services all be it in a different way.

With the use of technology and social media they have adapted way of supporting and interacting with people, and have put together resources that may be of use to others

What's concerning?

Citizens Advice are concerned some people living with the impact of a disability or health condition are not applying for disability or sickness benefits to help them manage financially.

Citizens Advice have seen a **drop in the number of people seeking help with applying for these benefits** which we think may be because people are not getting their health diagnosis or misunderstandings that they don't need to apply now as assessments are suspended. You do not need a diagnosis to apply. Please contact **Citizens Advice now to avoid future issues**. They are anticipating a backlog of claims, from this slowdown, which in turn may cause longer delays in local people getting vital money to meet the extra costs of disabilities and long term illnesses.

Insight from NHS Volunteers Responders suggests there is still volunteering capacity to support local people, but responders are not being contacted (18 responses from volunteers, all waiting to get asked to support).

Our actions:

- We continue to repost information on social media and will ensure we also encourage people to contact Citizens Advice for support around benefits.
- We will be putting forward a joint proposal with our Healthwatch colleagues to utilise volunteers to remotely support residential and nursing home residents.

Health and wellbeing management

What's working well?

We've heard positive stories that show the difference staff within health and care organisations make when they have adapted their practices to keep families informed.

> My mother had to have emergency surgery yesterday (first week of May '20) at Worthing Hospital. Of course, no-one could visit her at the moment - but she has managed to keep in touch via her mobile phone. The staff *have been brilliant* (her words). They make a most excellent cup of tea. And she is recovering well.
>
> Most importantly - Mr (name given) called my father last night to let him know the surgery had gone well, and that my Mother was in recovery. I've never seen such relief and such appreciation as a result of a phone call. Thank-you Mr (name given) for doing that - I can't put into words just how much that meant to him. And thanks to all staff for continuing to look after Mum for us.

Others shared how great it has felt to have GPs and nursing staff listen to them and discuss options, without feeling rushed. This has been particularly important, it seems to people, when fearful about going to hospital.

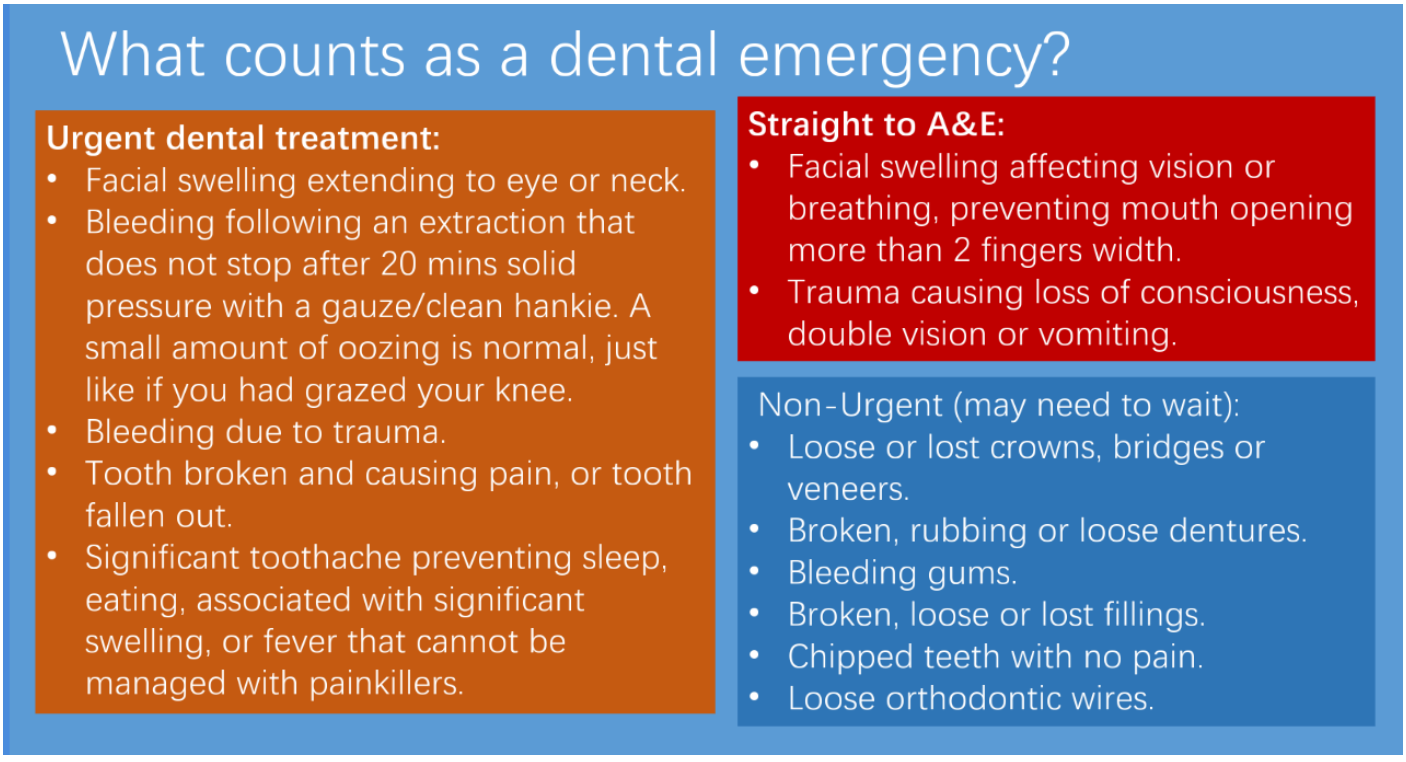
What's concerning?

Getting pain relief and treatment for **dental issues** has continued to be an issue, even after NHS England set-up facilities around the county to safely support people who needed urgent dental treatment.

The main issues seem to be around getting through to dentists and being able to get appropriate antibiotics (particularly where initial prescribed treatment fails to reduce the infection, or infection has spread further) and onward referral for treatment.

Our actions:

- We have provided insight to the Local Dental Committee and escalated to concern around communication (by local dentists and non-local 111 service) to NHS England.
- We have removed our Information and Advice guidance on our website, so we don't mislead people.
- We have updated our FAQs with the graph below to help people understand what they can expect and from where/whom. We will also be making sure this is widely available through social media.
- Our volunteers are this week reviewing the web and out-of-hours messages for dentists to see if we can support them to improve their information.



Other issues and updates

We've escalated the following with supporting insight as there appears to be additional support, or changes in communication needed:

- Non-emergency **transport for expectant mothers**, who are required to shield and therefore should not be using public transport

- **COVID 19 testing** - more information needed to avoid confusion and wasted time, and issues with accessing sites.

- Access to **Personal Protective Equipment** for carers and those that employ staff through Direct Payments, recognising this is a global challenge, but one that is having a negative effect on vulnerable people.

- **Morning After Pill** - the supply of this and the impact on others waiting to access the pharmacy whilst a consultation is carried out. Have since raised awareness on social media that pharmacists can carry out a telephone consultation and then a person can collect the medication.

- People have shared how they are **struggling to sleep** - we have drawn on many resources and personal experiences to create Sleeping Well During the Pandemic information that may help some residents.

- **Cancer** treatment - people have shared the impact the virus has had on them and their treatment. Healthwatch across Sussex are working with the NHS and Macmillan to host a virtual event so patients, and those worried about cancer can hear about the way services are adapting and have the chance to put forward questions.
  More information on this will follow shortly.

Whilst there is a need for sensitive and recognition that people have different approaches and beliefs around dying, we are also mindful of the impact difficult conversations are having because local people are sharing their reactions to calls about planning care. We are working on the evidence that people are currently taking their information largely from national sources, media and daily briefings - and therefore people can't escape that death is a key part of this pandemic.

This year Dying Matters Awareness theme is dying to be heard. It has always been very important that people can have conversations about their wishes and preferences around dying and we want to encourage people to think about what would be important to them and be in control of the conversations around care planning. You can read about an excellent tool you can use to think about end of life planning, from MyCareMatters.

Response from a local GP Practice: We thank Healthwatch for their insight and support to patients and surgeries at this new and difficult time. As has been raised in their report (#2), a lot of the actions and decisions that GP surgeries have taken (such as calling frail and vulnerable patients to ensure they are supported and have made considerations towards health-care planning) have been instigated from NHS England during the COVID-19 pandemic. We as a practice certainly would prefer to approach sensitive topics in a more timely and personal manner, but due to strict advice and guidance from 'up above' we often have to perform in ways that are not ideal. We understand the difficult decisions this may cause certain patient groups and have taken the decision to alter the NHSE advised approach towards this topic based on feedback received.

How this insight will be used?

We recognise that all health and care services are under pressure at this time and have had to adapt their ways of working. We will share this report with the local NHS, local Government and other providers to help them understand where things are working well and services are adapting to meet peoples' needs, and to help them identify any gaps.

For help, advice and information or to share your experience

We're the independent champion for people who use health and social care services. We're here to find out what matters to people and help make sure their views shape the support they need. We also help people find the information they need about services in West Sussex.

ADVICE AND INFORMATION

Here to help you on the next step of your health and social care journey

We've the power to make sure that the government and those in charge of services hear people's voices. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them.

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