

Healthwatch

Voices

Your views on your health and care services in Devon: Spring 2017



Special feature
**Young People
and Mental
Health**

In this issue:

Tackling Loneliness

Service Change

End of life Care

We welcome all contributions* to Healthwatch Voices but regret that we cannot guarantee publication and we reserve the right to edit for reasons of space or style.

To contribute an article, please email info@healthwatchdevon.co.uk

*Published items do not necessarily represent the views of Healthwatch Devon

Articles may include personal accounts which have been anonymised.

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Contents

In this issue	1
Special Feature Young people and mental health	2 - 3
Changing local health and social care services	4 - 5
Tackling Loneliness	6 - 7
Libraries Unlimited	8
Patient Experience at Northern Devon Healthcare NHS Trust	9
Caring until the end...	10 - 11
Finding your way through the system	12
Feedback Form	13

In this issue...

The NHS was set up as part of a welfare state that aimed to look after its citizens "from cradle to grave". In this issue of Voices, we're looking at services for young people, for adults, and for people at the end of life.

As always, our concern is with what works - and doesn't work - from the point of view of patients, carers and families. Medical science, happily, continues to improve. Political arguments about funding for health and care services, unhappily, continue to rage. In the middle sit the patients - the people whose taxes fund the NHS, and who have a right to expect good service.

In this issue, we hear about young people's experiences of mental health services. Adolescence can be a difficult time, and in Devon - as elsewhere around the country - young people can struggle with anxiety and depression, sometimes linked to things like eating disorders and self harm. If they get help early enough, a full recovery is perfectly possible. That is why good access to good mental health services really matters. You can read more on pages 2 - 3.

You might think that "end of life" services take us right to the other end of the age range. And it's true that in Devon, with its ageing population, we need to think carefully about how and where elderly and very frail people want to die. But on page 10 - 11, we hear from a mother whose daughter died from cancer at a young age, and for whom the local hospice was a source of great personal comfort, as well as excellent medical care for her daughter's last days.

Our other pages cover loneliness, patient experience in Northern Devon, and much more besides. Within a health and care sector that can feel caught between politicians, accountants and the media, it is vitally important that the patient voice gets heard. Keep your stories coming, and we'll make sure they get through.



Miles Sibley, Executive Director

Alerts and escalations

We will always pass on matters of serious concern to the relevant authorities. Recently we have escalated concerns about the following:

- A formal complaint about a GP practice
- A referral to the safeguarding team regarding a care worker
- Concerns of poor care for an elderly dementia sufferer.

Healthwatch Devon on the road

Coming to a town near you!

We'll be travelling the county this summer with our team of volunteers. We are looking forward to hearing your views about the health and social care services in your area.

Clare, our volunteer co-ordinator says

"Everyone has a story to tell, and we want to hear yours!"

"Whether it is about your fantastic GP or an unpleasant stay in hospital, we want to hear it all - because your experiences matter!"

"So come and say hello, share your story, and help shape services for the future."



Come and see us at:

- Exeter Pride 13 May
- RESPECT 3/4 Jun
- Axe Vale 17/18 Jun
- Mid Devon 22 Jul
- Totnes 30 Jul
- North Devon 2 Aug
- Okehampton 10 Aug
- Holsworthy 24 Aug
- Widecombe 12 Sep

Young People and mental health

In January, Prime Minister Theresa May announced more help for schools and health services to deal with the “hidden injustice” of mental illness. At the same time, Jeremy Hunt, Secretary of State for Health, acknowledged a “black spot” in mental health care for children and young people, and “massive worry for parents”.

On these pages, we look at mental health services in Devon, and the experiences of young people and their families.



Our stories ...

Mental illness can be difficult to talk about, so we have helped young people to put together a series of short films that enable them to tackle mental health topics through music, drama and dance. The films are designed as a “pick and mix” resource that can be browsed through by young people, or used by teachers, youth workers and others to help air the issues and prompt discussion.

A further film, “Made of Rainbows”, was put together by young people who wanted to talk about their experiences of coming out as lesbian, gay, bisexual or transgender. They explore the effects on their mental and emotional wellbeing, and talk frankly about how it feels to try to get help from the health services.



You can view the films on our YouTube channel. Search Healthwatch Devon.



What families say ...

Two national reports have shown how hard it is for families to get support for young people needing help for mental illness. “Time to Deliver” by the Commission on Children and Young People’s Mental Health found that specialist mental health services are, on average, turning away almost one in four children and young people referred for treatment by teachers or GPs. They also identified a postcode lottery of waiting times for those whose referrals were accepted.


“There for You” is a report by the Association for Young People’s Health, based on interviews with 300 parents of young people with mental health

problems. They found that parents struggled with waiting times, with health professionals not believing there was a problem, and with being excluded from the treatment process.

Nearer to home, Healthwatch Devon works with young people to help get their needs heard by NHS managers. Mental health is always one of their top concerns, often linked to eating disorders, worries about drugs and alcohol, and self harm.

We have taken feedback from young people, and their parents, to the Devon Health and Wellbeing Board, which oversees health service strategies for the county.

Common issues reported to us were:

 <p>Poor communication</p> <p>Parents not feeling well informed</p>	 <p>Long delays for assessments</p> <p>for child and adolescent mental health services</p>	 <p>Not knowing who to contact</p> <p>within mental health services for information</p>
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Early help for mental health

Early intervention is an important part of tackling the rising demand for mental health support which has been stretching CAMHS services across England. The average wait in Devon is just over 6 weeks for a routine appointment, against the NHS average of more than 20 weeks. A new scheme called Early Help 4 Mental Health (EH4MH) is crucial to keeping waits down and improving access to mental health support.

Three quarters of schools in Devon are signed up to Early Help 4 Mental Health. The scheme builds skills and knowledge about mental health among school staff, and gives students easier access to face-to-face and online counselling.

EH4MH covers common mental health issues, from anxiety to bereavement support and self-harm, offering ‘early help’ support to avoid more serious issues developing. The online counselling service is available 24 hours a day.

One student said: “It was all about what I wanted to get from the sessions we had. I wasn’t pushed in any direction and I liked that. I was offered some helpful ways of coping in certain situations so I could go home and practice should I need to’

More information about the EH4MH service, and how to access support, is available at www.eh4mh.co.uk.

Do you have experiences of mental health services for young people in Devon? We’d like to hear from you. You can contact us anonymously if you like. We’ll make sure your feedback - good or bad - is passed on to people who manage mental health services in Devon.

Changing local health and care services

... while national leaders change their minds

Regular readers of this magazine will know that big changes are being planned for Devon's health and care system.

There have been consultations in South Devon and Torbay about the future of community health services, including community hospitals. Similar consultations have also been going on in East Devon. And right across Devon at the moment, other services are up for review, including stroke services, maternity services, and urgent and emergency care.

It's all part of something called the "Sustainability and Transformation Plan" or STP for short. Devon's STP is one of 44 similar plans that have been prepared across the whole of England. It's a national scheme, driven by NHS England, which says that health and care services have to change to keep up with rising demand, combined with financial pressures.

The difficulty for managers of health and care services - and for the general public - is that the situation at the national level keeps changing. Here are two recent announcements...

On the 3rd March, Simon Stevens, Chief Executive of NHS England, said, "there can no longer be an automatic assumption that it's OK

"there can no longer be an automatic assumption that it's OK to slash many thousands of extra hospital beds"

Simon Stevens, NHS England

to slash many thousands of extra hospital beds - unless and until there really are better alternatives in place for patients."

Stevens went on to say that from April onwards, NHS organisations will have to meet three new conditions before being allowed to carry out significant hospital bed closures.

This sounds like good news. But perhaps NHS managers - and patients - could be forgiven for saying "Thank you Simon. But why didn't you say that a year ago?"

A few days later, Chancellor Philip Hammond presented a budget that offered an extra £2 billion over three years for adult social care. Again - good news - particularly as a lot of the planned changes to local health services depend on social care services being able to look after more elderly people in their own

homes. But this, too, has sent local health and care managers back to the drawing board to rethink their plans.

"I am committing additional grant funding of £2 billion to social care in England"

Philip Hammond MP

Healthwatch Devon believes that local health and care services need to change and develop, in response to changing needs from the local population. We are encouraging Devon residents to be part of the debate - to talk to health and care managers in public meetings, focus groups and on-line. Recent events show that if enough people speak up, national leaders will change their minds.

Keep in touch with the debate. Visit devonstp.org.uk or sign up for our Voices magazine and monthly e-bulletins.



NHS Consultations ... What should you expect?

There will be more consultations on changes to health and care services as we go through 2017, and we want people to know how they can have their say. We'll be advertising public meetings and on-line consultation opportunities in this magazine and on our website. But we also want to help people understand how NHS consultation processes work, and what their rights are.

We have published a simple guide: "What to expect from an NHS public consultation". It explains the steps the NHS has to take to ensure that patients and public are properly informed about possible changes to services. And it says what you can do if you are not happy with the way a consultation has been carried out.

Alongside that, we have produced an information sheet on the role of Healthwatch in consultations. This explains how we can encourage people to have their say, and can offer observations on how consultations are carried out. But we cannot get involved in political arguments and campaigns.

For a copy of the guides, please visit our website or write to us at Healthwatch Devon, FREEPOST RTEK-TZZT-RXAL, First Floor, 3 & 4 Cranmere Court, Lustleigh Close, Matford Business Park, Exeter EX2 8PW.



Help us to

tackle loneliness

Devon's health and care services are aiming to look after more and more older people in their own homes. That's good for people who don't want to be taken into a hospital or care home. But it can mean that some people spend long days, in between brief care visits, feeling lonely and isolated. Here are some ways in which local community groups are helping...

The Kingsbridge and District Tinnitus and Hard of Hearing club was set up by two very determined ladies who wanted to help local people with Tinnitus. The condition, often described as "ringing in the ears", can have devastating effects on people's lives, ruining their ability to enjoy time with family and friends. The Kingsbridge group has 28 members and has had requests for advice and assistance from all over the country. They meet bi-monthly with a hearing therapist, and help people to get together for social occasions and support.



In Barnstaple, **Libraries Unlimited** are encouraging people to get together in a 'Feel Better With A Book' group, and a 'Library Memory' group. It's not all sitting down - a 'Walking for Health' is another popular activity that enables people to become more physically active while having an opportunity to chat to fellow walkers.



The **LGBT Number 3 Social & Support Group** aims to tackle social isolation within the **LGBT+ community**.

Shawn Blackstock, the group's co-founder says,

"Our Men's Group has been going from strength to strength. We started with a few friends getting together for a cup of coffee. The group started to grow, and moved to monthly meetings. Now we go out for meals, and enjoy day trips etc. We also provide support through counselling, befriending, and hospital visits. We are currently working on a project called "Arm in Arm" bringing organisations together to tackle the issues of social isolation and raise alcohol awareness within the LGBT+ community."



These groups are great examples of how people can act together to tackle loneliness and isolation. Healthwatch Devon is bringing these, and other examples, to the attention of health planners and managers of care services. We want them to support community efforts to get people together and keep them well.

We're keen to hear from people right across Devon about how "loneliness" affects people's health, and how local communities can help.



In Kingswear, nearly 50% of properties are holiday or second homes. So for elderly and housebound residents, there isn't always a friendly neighbour to call on.

The **Kingswear 2-4 Tea Club** was created to bring older people together once a month in the village hall for tea, cake, chatter and companionship. Free transport is offered to help those who are housebound. The group currently has 30 members and has been running for 4 years.

Look out for our " Help us to tackle loneliness" feedback boxes in GP surgeries, libraries, Citizens Advice offices, some churches, and other community venues. You can pick up one of our postcards and use it to tell us about your ideas and experiences.

Alternatively, you can call our Freephone number 0800 520 0640 to tell us your views.

For more information about our project please visit our website healthwatchdevon.co.uk/loneliness.

Ask people to name a local health service, and it's unlikely that many would mention the library. But if your image of libraries is rows of dusty books and a stern faced librarian, think again. Libraries Unlimited is the new name for Devon's library service, and - as the name suggests - it's about books and much more...

Libraries are one of the few remaining community spaces where people are welcome to spend as much or as little time as they wish. As a safe and open place for all, libraries can play an important part in the health and wellbeing of local communities.

With a national rise in homelessness, libraries are sometimes used by people looking for a comfortable space to spend the day. Staff in Exeter Library have a regular visitor who enters the library each day, as soon as the doors open. He spends his day reading, and sharing a friendly smile or small-talk in a welcoming and warm environment.

One of the most important services on offer in Devon is the mobile library, which serves over 400 rural communities. New research suggests an increasing number of people in the UK feel lonely and isolated on a daily basis, so mobile library services offer a valuable opportunity for people in rural communities to get out and talk whilst browsing the bookshelves.

The Outreach Library Service (provided by The Royal Voluntary Service working with Libraries



Unlimited) can go even further - taking books and other library resources to the homes of people who, through illness or disability, find it difficult to get out of the house.

Libraries also offer community focused groups and events, the majority of which are free to attend. Cullompton Library, for example, hosts a support group for people with fibromyalgia, a long-term condition that causes pain all over the body. The group come together to share their own experiences and ways of managing the condition, as well as to better understand the condition.

The Reading Well Books on Prescription initiative aims to help people to understand and manage their mental health and wellbeing, or seek support for a friend or relative. In 2015, 85% of those who had borrowed a title from the

adult mental health list said the book had made them feel more confident about managing their symptoms. In addition, libraries offer books written especially for young people, with information on common mental health conditions including depression, anxiety and stress. In Devon, the Reading Well series for young people overtook the success of other ranges, with 2,500 loans in six months, taking the total for Reading Well book loans to more than 8,000.

For Libraries Unlimited, health and wellbeing is a crucial element of the services on offer, supporting people of all ages throughout Devon.

For more information on any of the above, visit librariesunlimited.org.uk or contact enquiries@librariesunlimited.org.uk

Patient experience at the Northern Devon Healthcare NHS Trust

The Northern Devon Healthcare NHS Trust runs services including the District Hospital at Barnstaple, other community hospitals across North Devon, and community teams that deliver nursing, therapy and care in people's homes. They routinely ask patients for feedback about their services - but recently asked Healthwatch Devon to help them get a more in-depth view of what it's like to be a patient of the Trust. We ran three focus groups, in Bideford, Barnstaple and Ilfracombe to explore topics such as communication, availability of staff, co-ordination of care and self-care.

Here's what we heard...

Overall, people were very positive about their experiences as patients with the Northern Devon Trust. They were appreciative of the treatment they had received, particularly when good medical care was matched with kindness from staff. They also liked the fact that the Trust had asked for their views, and was ready to listen and learn.

People liked:



Quick response: *3 year old child referred to paediatric ward. Very good - immediate checks and medication. Discharged with a helpful information sheet.*

Good communication: *Nurses were pretty well informed so I didn't have to keep telling the same story.*

Good co-ordination between different parts of the service: *GP, x-ray and physio all very quick and all records transferred well.*

Kindness: *Ward very good - very friendly and ask what you'd like to eat.*

People didn't like:



Delays: *If you don't know the system and you aren't able to speak up you can be waiting much longer.*

Poor communication: *Clinicians use too much jargon and acronyms and don't realise they are doing it.*

Poor co-ordination: *Received letter-after-letter changing the date and time of my operation - hard to keep track and know which is right as two arrived on the same day*

Unhelpful staff: *Can be 'computer says no' - not always an idea of 'service' or 'customer care'*

The two-hour focus group sessions allowed us to talk at length about these, and many other issues. There were some good ideas about how to make a good NHS service even better. One was that family, friends and carers have an important part to play. They can double check information, and remember what questions to ask. This really matters for patients who are anxious or confused - and it can help the doctors as well as the patient.

A full report on all the focus group discussion has gone to the Northern Devon Healthcare NHS Trust, and will be used to help staff think about how they can give patients the best possible experience of care.

Caring until the end...



Most people go to the NHS expecting to be made better. But every year, 6,500 people in Devon are receiving medical care at the end of life. There is still a need for excellent medical care, even when people are dying. But kindness and sensitivity to the patient - and to their family and friends - is every bit as important.

Healthwatch Cornwall recently published a report entitled "A Good Death". They found that patients who know that they do not have long to live still want to carry on with normal activities for as long as possible. They would like to be treated with dignity, as an individual. At the end, they want to be pain free, and to have family and friends with them.

In Devon, the South Devon and Torbay Clinical Commissioning Group (CCG) have been carrying out a survey to find out more about people's experiences of end of life care. The results will be used to help make improvements to end of life care services for patients, and their loved ones.

Healthwatch Devon will shortly publish a report, based on feedback that we have had from Devon residents, which indicates that there is a need for more consistency when it comes to the care given at the end of a person's life.

Stories that we have heard demonstrate that where care is good or exceptional, it is because the physical and emotional needs of the patient and the family are being met. It is also because people are helped to make informed choices about their care, and their care is well managed and personalised.

What do patients want from end of life care?

-  **To be heard**
-  **To have family present**
-  **To be pain free**
-  **Treated with dignity**
-  **To do normal activities for as long as possible**

A mother describes the care she and her daughter had in the Exeter hospice

My daughter Ellie died a year ago, aged 33, in the hospice in Exeter. She had been diagnosed three years earlier with cervical cancer, while she was pregnant.

It was difficult to treat the cancer during the pregnancy, as there was a risk that the chemotherapy would harm the baby. A safe treatment was attempted but Ellie went into anaphylactic shock.

The baby was born safely at 30 weeks, and Ellie then went straight into full chemotherapy at the Royal Devon and Exeter hospital. The staff on the Cherrybrook ward were amazing. But after a while, the treatments stopped working.

Ellie was stubborn. She didn't give up easily. She managed to get herself on a clinical trial at the Royal Marsden hospital in London. She would drive herself up to London, have treatment all day, then drive back to Devon. She also wrote a blog about her experiences, which she called "Diary of a Lab Rat". The trial went well to begin with, but after 10 months the treatment, promising at first, failed to deliver.

Ellie got herself onto a second trial, but the side effects were terrible, and started compromising her immune system. She went back to the RD&E for further chemotherapy, but it was ineffective.

In the last stages of her illness, Ellie kept getting infections and was hospitalised regularly. She was becoming weaker. The oncologist was wonderful, with reassuring words, even though we knew the end was coming.

When Ellie went into the hospice, I was able to go in and stay with her. It was a lovely place, with a calm and peaceful atmosphere. The room had a view out over a garden. Hospitals are busy places, but in the hospice, it felt as though the staff had all the time in the world. Once, when I was upset at 2am I was taken into the nurses' room for a cup of tea and a chat.

On the last morning, I was woken up early to be with Ellie as she died. The nurses waited, and let us have time with her after she had gone. There was no rush. Some of the nurses were crying. It's good that they can be open about their sadness. They were such warm and friendly people.

Some people say that when it comes to their time, they want to die at home. But you have to think of the practicalities. Home might be a small house, without room for extra people and equipment. You can have distractions - people calling, or pets to look after. You can't be sure of getting instant medical assistance if you need it.

The hospice was a place of calm, where we could be together in my daughter's last days, without distractions, and feeling safe. While we were there, the Care Quality Commission was inspecting the place. I said how good it was, and the inspector said we should have bigger hospices. I said no - bigger would mean more beds, more staff, more visitors, and it would start feeling like a hospital. We need small hospices - but more of them.

Do you have experience of being with someone while they were receiving end of life care? We'd like to know what was good - and what might have been better - from your point of view. We can make sure that your comments are heard by people who run end of life services - and you can contact us anonymously if you want.


Contact us on 0800 520 0640 or visit healthwatchdevon.co.uk

Have your say

on local health and
care services




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