

Patient Experience

1. End of Life Clinical Programme Group

1.1 Background

The End of Life Care Clinical Programme Group (CPG) was created 18 months ago to deliver the priorities set out in the End of Life Care Strategy 2016-19. This strategy made a commitment to ensure the highest quality end of life and palliative care services are available to all who need it irrespective of diagnosis, age, gender, ethnicity, religious belief, disability, sexual orientation and socio-economic status.

Integral to any service improvement or re-design work is listening to people with experience; this is particularly true in relation to end of life care services. Dame Cecily Saunders, the founder of the Hospice movement, said “How people die remains in the memory of those who live on”.

We will only die once which means there is only one chance to ensure people, and those closest to them, have a ‘good’ experience at the end of their life and in death. To support the delivery of the End of Life Care Strategy the CPG decided, therefore, to recruit two people with experience (they cared for loved ones who died in Gloucestershire) along with a Healthwatch representative, to be members of the End of Life Care CPG.

1.2 Local engagement

The first two CPG meetings were workshops that explored what a ‘good’ experience of end of life care might look and feel like for people, their carers and families. In these workshops, patient representatives were able to share their experiences, both good and bad, with health and social care professionals.

An End of Life Care programme of work, with many service improvement projects, was developed following the workshops. Patient and Healthwatch representatives are included on many of these projects as part of the Project Team. They choose which projects they want to be involved with, usually as a result of their individual experiences, where they feel they will most add value and make a difference, for example:

- Involved in project to record and share electronic DNACPR (Do Not Attempt Resuscitation) and other end of life care preferences, to prevent inappropriate resuscitation. This was because a person they cared for was so worried about being resuscitated against their wishes they wrote DNACPR on post-it notes and stuck them around their bed and throughout the house in case emergency services were called;

- Involved in project to roll-out anticipatory (or 'Just in Case') end of life care medication because the person they cared for wasn't able to access timely pain relief when it was needed.

Of particular note was a project supported by patient representatives but more extensively, by Healthwatch. The CPG wanted to understand what holistic (non-clinical) support at end of life was available locally and what people thought was needed (i.e. where the gaps were). Healthwatch Gloucestershire undertook a range of engagement exercises (including a survey) with people who were caring for, or who had cared for, people at end of life. The resulting report was published on their website: <https://www.healthwatchgloucestershire.co.uk/reports-publications/>

1.3 What we learned/outcome

Having patient and Healthwatch representation on the CPG ensures that the members of the CPG (i.e. health and social care professionals, commissioners and colleagues from the voluntary and community sector) remain grounded and sighted on what is important and makes a difference to people, their carers and families at end of life.

The Healthwatch engagement work contributed to the final report from the holistic support project. The key themes emerging were:

- Information in the same place where it is easy to find and navigate;
- Information on the physical changes at the end of life and what carers and families might expect;
- Psychological and emotional support available to carers/family as well as patient;
- Post death practical advice and bereavement support (not just immediately after the death but ongoing to help the person cope with loneliness etc.);
- Even when information is given it may not always be taken in or remembered at a time when people are in such stressful and upsetting circumstances.

1.4 Next steps

The CPG has developed leaflets offering good practical advice including information about the physical changes which might be expected at the end of life, but these are not being accessed by those who may have benefitted from them. The CPG will, therefore, undertake a review of:

- where we are locating copies of the leaflet and how we can ensure these are more accessible; and
- how we can raise awareness of this information amongst professionals.

Patient and Healthwatch representatives are about to start a new project which will provide a great opportunity to improve awareness about end of life care in the community. This project will enable people who are caring for someone at the end of life to be more informed and better prepared about what to expect in the final few weeks and days.

Working with a local domiciliary care provider, they will develop a 2 hour education and training session to be delivered in community settings to people who are caring for someone at end of life. The patient representatives have often told the CPG “If I had known, then I would have been better prepared as to what was going to happen next”. Their experiences and insight into what they would have found helpful and useful to know in the last few weeks and days will be invaluable in developing this resource.

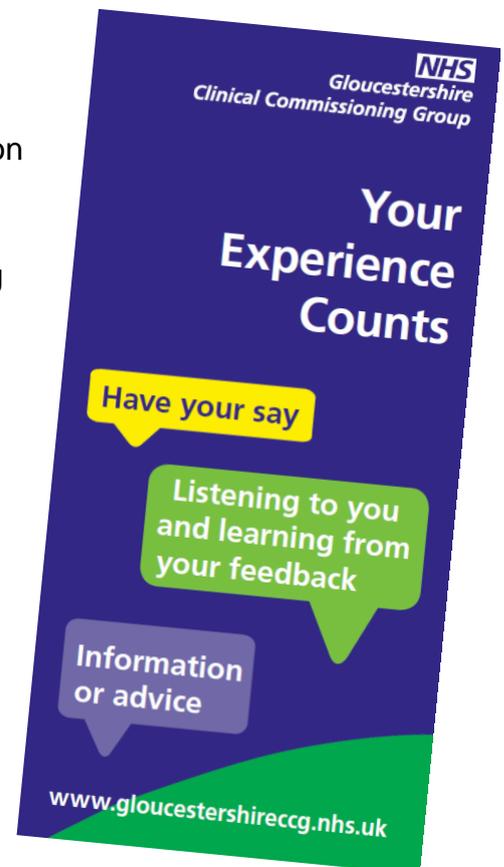
The CPG is extremely grateful to the patient and Healthwatch representatives for their desire to make a difference, their courage to speak openly and freely about their deeply personal experiences and for the time they are prepared to give to support the work of the CPG.

2. Primary Care Patient Advice and Liaison Service

2.1 Background

NHS Gloucestershire CCG (GCCG) was established in 2013. At that time GCCG had a Patient Advice and Liaison Service (PALS) transferred from the Gloucestershire Primary Care Trust, providing advice and support to local people in relation to problems they might be experiencing relating to commissioning decisions or primary care services. However, in 2013 responsibility for commissioning primary care services became the responsibility of NHS England and a decision was taken nationally for a central all-England PALS to be set up to handle all primary care enquiries.

A local decision was required regarding handling of PALS enquiries related to our residents’ experience of local primary care services and our Governing Body took the decision in 2013 to invest in the continuity of a local PALS service; which also offer a formal commissioning complaints handling service; maintaining a responsive local offer for Gloucestershire residents.



Member practices recognised at the earliest stage of the establishment of the CCG the importance of local resolution for patients' concerns and the potential to learn from the experiences of local people collected through PALS.

2.2 Local Experience

The number of contacts to GCCG PALS has steadily increased during 2018, with just over 800 people contacting the service – a rise of almost 25%. PALS Case studies are a routine feature of Quality Reporting to the GCCG Integrated Governance and Quality Committee. The three examples below highlight the range of experiences shared with PALS and action taken:

Case Study 1: PALS supported a Patient who had been struggling to get their medical records updated following gender reassignment. PALS contacted the practice and supported them with submitting the required documentation to Primary Care Support England. As a result of this enquiry appropriate information and weblinks have been added to g-care to ensure that practices follow the appropriate processes in a timely manner.

Case Study 2: Over the last twelve months there have been some significant changes in the prescribing of some over the counter medications. There have also been other national changes in prescribing practice, for example FreeStyle Libre flash glucose monitoring systems, which have resulted in a flurry of calls to GCCG PALS.

In the case of FreeStyle Libre monitoring, this was made available via NHS prescribing across the UK, but with access to the device subject to local CCG Guidance. NHS Gloucestershire CCG does not recommend the routine NHS provision of the FreeStyle Libre system, or the prescribing of FreeStyle Libre sensors/strips in Gloucestershire. The NHS Gloucestershire CCG Prescribing Guidance recommends that adult patients are only initiated on Freestyle Libre by a Hospital Specialist and that they meet the clinical criteria set. GCCG PALS received well over 50 enquiries relating to the prescribing policy for this product.

In dealing with this type of enquiry, GCCG PALS ensure that the patient has access to all of the relevant information and policy documentation, facilitates personal written responses or call backs from pharmacy leads as appropriate and provides advice on appeals process and Individual Funding Requests where required.

2.3 What we learned/outcome

As the three examples above demonstrate we recognise that retaining a local PALS service for commissioning and primary care in Gloucestershire is crucial. Patients acknowledge that PALS intervention has helped them and they say they have felt supported at an earlier stage, negating the need for formal complaints to be made.

2.4 Next steps

Opportunities in 2019 to be explored include introduction of a more systematic evaluation of the experience of users of the PALS service and collection of more detailed demographic information about those individuals who proactively access the service, based on the NHS England Surveying complainants Toolkit <https://www.england.nhs.uk/surveying-complainants/>. This will enable us to develop targeted communication and promotional materials to reach groups which may currently not be aware of, or are choosing not to access, the service.