

A meeting of the Patient Council will be held on **Wednesday 26 February 2020 at 6.00pm** at Hillder House, 49 – 51 Gawber Road, Barnsley, S75 2PY

**AGENDA**

ITEM	SESSION	LEAD	TIME
1.	Welcome and apologies	Chair	6.00pm
2.	Update of the previous meeting held on 29 January 2020	Chair	6.05pm
<b>PRESENTATIONS / QUESTION &amp; ANSWER (Q&amp;A) SESSIONS</b>			
3.	<p>An introduction to the role of the Barnsley Continuing Healthcare (CHC) Team</p> <p>-Presentation followed by question and answer session. This was requested by Patient Council members at a previous meeting. The session is aimed at providing an overview of what CHC services are, how they work in Barnsley and for you to ask any questions and provide feedback on anything you've picked up from your practice group discussions in relation to CHC services.</p> <p>For some information ahead of the meeting there is a short video and more information explaining what CHC is on the <a href="#">Barnsley CCG website</a>.</p>	Sheena Moreton - Continuing Healthcare Operational Lead, CCG	6.10pm
<b>GENERAL</b>			
4.	<p>Any other business</p> <p>- Public Sector Equality Duty Update</p>	Chair  Emma Bradshaw, Engagement manager, CCG	7.00pm
5.	<p><b>Date and time of the next meeting:</b></p> <p>The next meeting will be taking place on Wednesday 25<sup>th</sup> March 2020, 6.00pm at Hillder House, 49 – 51 Gawber Road, Barnsley, S75 2PY</p> <p><b>Future meeting dates for 2020:</b></p> <p>Wednesday 29<sup>th</sup> April 2020            Wednesday 27<sup>th</sup> May 2020            Wednesday 24<sup>th</sup> June 2020            Wednesday 29<sup>th</sup> July 2020  <i><b>No meeting in August</b></i></p>		7.15pm Close

**For enquiries or to send apologies please contact:**

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**Minutes of the Barnsley Patient Council meeting held on  
Wednesday, 29 January 2020 at 6.00pm in the  
Boardroom, Hilder House, Barnsley CCG, 49/51 Gawber Road, Barnsley**

**PRESENT:**

Chris Millington ( <i>Chair</i> )	Barnsley Clinical Commissioning Group Lay Member for Patient & Public Engagement
Ben Cox	The Grove Surgery PRG
Alan Higgins	Barnsley Hospital Public Governor
Alan Jones	Hollygreen Surgery PRG
Terry Kendall	Penistone Group PRG
Margaret Sheard	White Rose Surgery PRG
Philip Watson	Patient, Hill Brow Surgery PRG
Nell Dyke	St Georges Practice PRG
Janet Neville	

**IN ATTENDANCE:**

Siobhan Lenzionowski	Lead Commissioning Manager, Barnsley CCG
Kirsty Waknell	Head of Communications & Engagement, Barnsley CCG
Sara Andrews	Macmillan Lead Cancer Nurse and Macmillan Project Manager for the 'Living with and beyond cancer' Barnsley Hospital

**APOLOGIES:**

Colin Wilkinson	Park Grove Medical Practice PRG
Gill Partington	Ashville Medical Centre PRG
Garth Heyworth	Wombwell Surgery PGR

Agenda Item	Note	Action	Deadline
<b>PC19/07/01</b>	<b>WELCOME AND APOLOGIES</b>		
	The Chair welcomed everyone to the meeting and apologies were noted.		
<b>PC 20/01/02</b>	<b>MINUTES OF THE PATIENT COUNCIL HELD ON 27 NOVEMBER 2019</b>		

	<p>The minutes of the previous meeting held on 27 November 2019 were approved.</p> <p>Kirsty Waknell and Chris Millington displayed a photograph from the recent nurses in general practice awards and thanked everyone who had nominated someone from their practice for the patient's choice award.</p>		
<p><b>PC 20/01/03</b></p>	<p><b>PRESENTATIONS AND DISCUSSION SESSION</b></p>		
	<p><b><u>Refreshing our End of Life Care (EoLC) Strategy for adults in Barnsley</u></b></p> <p>Siobhan introduced Sara Andrews from Barnsley Hospital and Alan Higgins who ran the session. To start things off, Siobhan asked the group if they had thought of things other than cancer when they think of end of life.</p> <p><u>Feedback from presentation and discussion.</u></p> <ul style="list-style-type: none"> <li>• Comment - Sepsis kills more people than cancer.</li> <li>• Q – What does the data tell us?</li> <li>• A – We know that more people die in hospital than other areas.</li> <li>• Q –How is talking to us going to help us?</li> <li>• A – This is one group of many people we'll be talking to get feedback and what comes out of these discussions is really helpful, as we can start to see things through other people's experiences.</li> </ul> <p>Comments throughout the presentation:</p> <ul style="list-style-type: none"> <li>• Need to involve families of people who have had something where they can't communicate – dementia for example.</li> <li>• Care plans are important and people need to put the wishes of the person in place – no good having a care plan and then ignoring it.</li> <li>• Need to consider the role of staff in nursing and care homes when it comes to people's wishes.</li> <li>• Care homes and residential homes – stop sending people into hospital or A&amp;E</li> <li>• We should recognise people are on a range of how they deal with things</li> <li>• People here today are probably of an era where our age group are prepared to have a conversation – used to be 'doctor knows best'</li> </ul>		

	<ul style="list-style-type: none"> <li>• Do we have enough spaces in hospices for example to honour people’s wishes – how do we raise and deliver once expectations raised ...?</li> <li>• Do carers who come into people’s homes follow care plans – different carers each day who “don’t do things like that”.</li> <li>• What you need are good neighbours? That’s what helped me.</li> </ul>		
	<p>People then split into three groups to discuss in more detail. The feedback from each table included:</p> <ul style="list-style-type: none"> <li>• Communication is key!</li> <li>• Community support</li> <li>• Make plans – will making – conversations</li> <li>• Clear wishes</li> <li>• What do we know? (lay people/professionals)</li> <li>• Realistic</li> <li>• Making a difference</li> <li>• Advocate/point of contact</li> <li>• Signposting</li> <li>• “wrap around” approach to care</li> <li>• The people ‘left behind’</li> <li>• Power of attorney – finance – health &amp; wellbeing</li> <li>• Vulnerability</li> <li>• Reassurance</li> <li>• Thoughtful care</li> <li>• “It’s ok to talk about it”</li> <li>• “Don’t be afraid”</li> <li>• Train our staff/awareness raising</li> <li>• Want ‘them’ to know!</li> <li>• See and observe ‘other’s’ pain</li> <li>• Watching a demise</li> <li>• Promises made to other people</li> <li>• Lost closeness in our ‘village mortality’ stretch familial involvement</li> <li>• Difficult emotive subject</li> <li>• If expect death e.g. Reason can talk about it – age for example</li> <li>• We do in my family – do have conversations</li> <li>• 10 years paid for funeral – pre-payment – wanted to sort out so no argument in family</li> <li>• Use stories to open up conversation – people want to talk about own experiences first</li> <li>• stress free, comfortable death</li> <li>• language we use is really important</li> <li>• Had numerous conversations–wanted best for them</li> <li>• Emotive” – hard to talk about</li> <li>• Not taboo topic to us</li> <li>• Share information sooner</li> </ul>		

	<p>At the end of the discussion Siobhan, Sara and Alan thanked everyone for sharing their experiences and personal stories.</p> <p>The feedback overall will help support the design of the new strategy with some people's experiences being tied into stories which we would use in the future when developing services and improving experiences for people and feeding back to staff.</p>		
<b>PC 20/01/04</b>	<b>ANY OTHER BUSINESS</b>		
	There were no other items of business to discuss.		
<b>PC 20/01/05</b>	<b>DATE AND TIME OF THE NEXT MEETING</b>		
	<p>The next meeting of the Patient Council will be held on <b><u>Wednesday, 26 February 2020 at 6.00pm</u></b>, in the Boardroom Hilder House, 49 – 51 Gawber Road, Barnsley, S75 2PY.</p> <p><u>Future Meeting Dates 2020</u></p> <ul style="list-style-type: none"> <li>• <b>25 March</b></li> <li>• <b>29 April</b></li> <li>• <b>27 May</b></li> <li>• <b>24 June</b></li> </ul>		



**BARNSLEY**

**Patient Council**



**Welcome**

# On the menu.....

1. Celebrating: Barnsley General Practice Nurse Awards
2. Your Voice: Talking about dying matters
3. Take & share: Carers strategy



# Barnsley GPN Awards 2020



# Refreshing our End of Life Care Strategy for Adults in Barnsley

Presented by Alan Higgins ( Cancer Steering Group Public Representative), Siobhan Lendzionowski ( Lead Commissioning and Transformation Lead); Sara Andrews (Lead Nurse for Cancer and Palliative Care Barnsley Hospital)

# End of life care - what do we mean?

- End of life care is defined by NHS England as care that is provided in the 'last year of life'; although for some conditions, end of life care may be provided for months or years.

This includes people with:

- advanced, progressive, incurable conditions e.g. COPD
- general frailty and coexisting conditions that mean they are at increased risk of dying within the next 12 months e.g. heart failure
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events

## Ambitions for Palliative and EOLC

01 Each person is seen as an individual

02 Each person gets fair access to care

03 Maximising comfort and wellbeing

04 Care is coordinated

05 All staff are prepared to care

06 Each community is prepared to help

Ambitions for Palliative and End of Life Care, 2015

# Discussion Areas

## Part 1:10 Minutes

1. Would you feel comfortable discussing end of life care with those closest to you?
2. Why would you feel that way?

## Part 2: 20 minutes

1. How do we, as a local health and care community in Barnsley, make it easier and more comfortable for people to discuss death and dying earlier?
2. What are your suggestions of a measure we could have in the strategy for this area?

# Other Ways To Have Your Say..

- Patient and carer online survey  
[www.barnsleyccg.nhs.uk/haveyoursay](http://www.barnsleyccg.nhs.uk/haveyoursay)
- Paper copies available
- All responses are anonymous
- The closing date for feedback is  
Sunday 9th February 2020

# Patient and Carer Survey

- Would you feel comfortable discussing end of life care with those people that are the closest to you?
- Would you feel comfortable discussing end of life care with any of the following health and care professionals?
- If you are were at the end of life, or caring for someone who is, what things would be most important to you and your loved ones?
- If you have any personal experience of accessing end of life care in Barnsley either as an individual or for a loved one that you would be willing to share with us, it would be much appreciated if you could please provide details below.
- Are there any areas in relation to end of life Care in Barnsley that you feel could be improved upon?



THANK  
YOU! 😊