where everyone matters

Connected Palliative Care Partnership
End of Year Report 2016–2017

Sandwell and West Birmingham Hospitals NHS Trust

Sandwell and West Birmingham Clinical Commissioning Group
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Front cover image
The Connected Palliative Care team and partners come together to celebrate the first year of success.

1. Foreword
It has been a long journey in healthcare to give end of life experience for patients and palliative care the priority it deserves. It is therefore a matter of real pride that our Trust is at the forefront in changing this, in collaboration with community partners and our commissioners.

I am delighted to see the progress that has been made by the partnership team to get real improvements for patients and families. Early indications from our Care Quality Commission inspection in March 2017 underline the best practice being adopted here.

We recognise there is more to do, including in improving the consistency in recognising the key indicators where this approach is likely to be beneficial for our patients and their families and to ensure the end of life services are available and accessible to all within our diverse population. The extended contract term gives us the platform to build on the first class start the team has made.

This is an NHS success story of integrated care where the focus is clearly on what works best for patients and their loved ones.

Richard Samuda
Chairman
2. Introduction

In April 2016 Sandwell and West Birmingham Clinical Commissioning Group (CCG) commissioned a new end of life service following extensive public engagement and a detailed review of service provision. Prior to this local end of life care and commissioning was felt to be in need of improvement as locally were faced with the following key issues:

- 17 separate providers of EOL care for SWB CCG creating a confusing complex care environment
- Historical commissioning arrangements from the merger of 2 former Primary Care Trusts
- Lack of monitoring of quality due to constantly evolving services (i.e. pilots being mainstreamed etc.) and difficulty in ongoing development of service specifications which outlined key quality measurements
- Lack of co-ordination and cohesion experienced by patients and clinicians
- Confusion for patients and carers as to how to access care
- Lack of support in a crisis / urgent situation
- Inadequate end of life care for people with non-specialist care needs
- Duplication and gaps in care especially in people dying of non-cancer diagnosis and those living in care homes

Building on local and national End of Life Care Strategies the CCG released an innovative service specification focusing on Community based healthcare with the aim to create a coordinated and responsive End of Life Care Service for the diverse and complex population served by Sandwell and West Birmingham CCG. This competitive tendering process was won by the Connected Palliative Care Partnership, led by Sandwell and West Birmingham NHS Trust as the lead provider with the contract for the service to run for 5 (+2) years commencing on 1st April 2016.

This report sets out an overview of the new service model, and sets out how we are delivering and using the information collected to help with future challenges and opportunities.

Overview of the Partners and Care Provided

The Connected Palliative Care Partnership (see Figure 1):

- Sandwell and West Birmingham Hospitals NHS Trust (lead provider)
- John Taylor Hospice
- Birmingham St Mary’s Hospice
- Birmingham Age Concern
- Sandwell Crossroads
- Sandwell Cruse
- University of Birmingham School of Nursing

Aspects of clinical care provided by each partner for this service:

Sandwell & West Birmingham Hospitals Integrated NHS Trust

- Specialist Palliative Care Team consisting of specialist nurses, palliative medicine consultants and therapists in both City and Sandwell Hospitals and Sandwell community area.
- A new single point of access 24/7 coordination Hub
- 24/7 Urgent Response nursing and therapy Team providing rapid assessment and intervention for patients at the end of life meeting physical, social or psychological needs.
- Home from Home beds for end of life care in Leasowes Intermediate Care Centre

In addition Sandwell and West Birmingham NHS Trust includes an established district nursing service, 2 acute hospitals, community hospitals and speciality medical, nursing and therapy staff.

John Taylor Hospice, Erdington

Provides:
- Specialist community palliative care
- Complex symptom control inpatient beds
- Home from Home beds for end of life care
- Day hospice care services with specialist clinics

Birmingham St Mary’s Hospice

Provides:
- Specialist community palliative care
- Complex symptom control inpatient beds
- Home from Home beds for end of life care
- Day hospice care services with specialist clinics

Birmingham Age Concern

Support workers from Age Concern will visit people at home to support with light housework and shopping. They also and provide a welfare advice service.

Sandwell Crossroads

Support for people at the end of life and their family/carers through day and night respite and befriending services.

Sandwell Cruse

Deliver bereavement advice and support to relatives/carers, either face to face or by telephone.

University of Birmingham School of Nursing

Developed a service evaluation model involving quantitative and qualitative information to guide service development.
3. New Connected Palliative Care Service

All services provided within the contract are available to all patients with a Sandwell and West Birmingham CCG GP and thought to be within the last 12 months of life. In addition to existing services offered by our partners and SWBH new staff were recruited (See Appendix 1), the following new elements were funded and developed and are now embedded into practice:-

- **Single Point of Access Coordination Hub**
  It opened May 2016 and provides advice and clinical assessment/triage to professionals as well as signposting and advice to patients and carers. It is staffed 8am-8pm by an administrative and clinical team with overnight calls taken by the Urgent Response Team.

  The Hub:
  1. Coordinates all services within the partnership, for example visits from the specialist palliative care team, district nurse, admissions to hospice or home from home beds or respite care.
  2. Holds and maintains a register of patients across Sandwell and West Birmingham CCG who are recognised to be within the last 12 months of life. The register is held as a clinical caseload on the SystmOne electronic patient record which can be accessed by members of the Connected Palliative Care Partnership, GPs and other community teams within SWBH. The register includes details such as patient’s Advance Care Plans, medication and medical history to support clinicians delivering responsive care.

- **Palliative Care Urgent Response Team (URT)**
  General palliative care nurses and therapists delivering rapid assessment and urgent interventions caring for dying people and their families in their own home.

  This includes hands on care, symptom management and psychological support. The team aims to respond to all appropriate calls within 30 minutes of a referral. The team works closely with district nurses and the specialist palliative care team to ensure seamless pathways of care.

- **Home from Home beds for the last few weeks of life**
  The partnership meant that the number of nurse led home from home beds increased from 2 to 8 available beds; at SWBH Leasowes Intermediate Care Centre, John Taylor Hospice and Birmingham St Mary’s Hospice. The beds are for people at the very end of life who do not have specialist or acute needs but cannot die at home for any reason and would like to avoid acute hospital admission.
4. Service Activity and Performance

Over our first year we had:

- 1,000 patients registered on the new End of Life Care register over the year with access to the Connected Palliative Care service
- 7,590 Specialist clinical nurses face to face contacts in patients own homes and care homes
- between Nov 2016 and March 2017 the Urgent Response Team visited patients 1,141 times in their homes
- patients in the Home from Home beds for End of Life Care for 1,302 days
- patients in Specialist Hospice beds for 811 days (this includes John Taylor Hospice, Birmingham St Mary’s Hospice and other Hospices if patient choice)

The effectiveness of the service is monitored by our commissioners with a set of key Performance Indicators (KPI’s); which includes both information and quality measures. We have performed well meeting those connected to service operations such as speed in answering the phone, arranging care packages and meeting clinical need including avoiding unplanned hospital admissions, see Table 2.

Over the year we found the most challenging areas to achieve were:

1. how we ensure that we offer everyone the chance to talk about their future wishes, which is often described as Advance Care Planning (ACP)
2. how we deliver on outcomes connected to patients being able to achieve their preferred place of death (PPD) and place of care (PPC)

Considerable progress in these areas was made throughout the year with all three achieved by the end of the year (during quarter 4) see Table 1.

5. Feedback about the service

To ensure ongoing service improvement we are undertaking a service evaluation in partnership with the University Of Birmingham School Of Nursing interviewing 30 stakeholders, including Connected Palliative Care (CPC) staff and partners, community nurses, GPs, lay carers and patients.

All ten CPC staff interviewed acknowledged the importance of the service and could see the positive change it had made in people’s End of Life experiences. CPC staff felt that some areas required attention, such as clarification of roles within the CPC team and employment of more staff to increase capacity. It was also identified that communication within the CPC team and other healthcare teams needed to improve. CPC staff also felt that the community was not fully aware of the service and what it offers. These initial findings were discussed with the manager of the service and measures were put in place to address them.

We are currently analysing the remaining interviews with examples of patient and carer feedback below:

“The nurse who came to see us was lovely, explained everything and said she was there if we needed her for anything”

“Within an hour problem sorted”

“Everyone I have had contact with have been very professional” (August 2016)

“The care for my mother is fantastic. Thank you”

“We think the team are very good at this point very nice people. Thank you for the service” (October 2016)

“All nurses gave me good attention in particular Mandy whose service is first class” (December 2016)

“Very pleased with input from urgent response nurses, the Hub and end of life care facilitators” (January 2017)
“Hub were very helpful in finding an answer for me on behalf of a patient”
“Was able to address all concerns re equipment needs, pain relief advice and also they chased up information from oncologist” (February 2017)

“As far as we are concerned no improvements need to be made as the service we received at this difficult time was 100%”
“URT were fantastic, I will recommend them as a compassionate caring team”
“Everyone was above and beyond their duty and made me, my dad and family feel very comfortable” (March 2017)

Further data will be published when analysed.

All patients / carers are also offered a patient experience questionnaire which incorporates the friends and family test. In Quarter 4 we had 28 returns with friends and family score of 96%, with 100% likely to recommend the service to others (see Table 3).

### Table 3 Results of patient experience questionnaire Quarter 4 N=28

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were you satisfied with the standard of care you received?</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>Do you feel you have been treated respectfully?</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>Do you feel staff had the knowledge and skills required to deliver your care?</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>Did you feel staff delivered your treatment with confidence?</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>Were you involved in the decisions made regarding your cancer treatment?</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>Did you feel you had the opportunity to discuss your care and treatment?</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>Have you had the opportunity to discuss your wishes in an advanced care plan?</td>
<td>100</td>
<td>0</td>
</tr>
</tbody>
</table>

### 6. Our Service Users

Despite having a diverse population across Sandwell and West Birmingham our patient group is not representative enough of all our local community who are dying of lots of different causes and more work is required in 2017/18 to ensure we improve access for all place to address them.

1. The majority of our patients have a primary diagnosis of cancer

2. The majority of our patients are white British

3. We are not yet accurately recording data on all patient’s protected characteristics e.g. religion so we are unable to report fully on this aspect, an area identified as needing development.

### 7. Referrals to the service

Referrals to our service are predominantly made by professionals with re-referrals also made by patients and carers. Hospital doctors and GPs are lower than expected and further engagement with professionals is required. Detailed examination of the data also shows considerable variation between different GP practices.

### Table 4 Percentage referrals by referral source

<table>
<thead>
<tr>
<th>Referral Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist Palliative Care Team</td>
<td>31%</td>
</tr>
<tr>
<td>Specialist Nurse</td>
<td>29%</td>
</tr>
<tr>
<td>Carer</td>
<td>15%</td>
</tr>
<tr>
<td>Ward Nurse</td>
<td>10%</td>
</tr>
<tr>
<td>GP</td>
<td>4%</td>
</tr>
<tr>
<td>Hospital Doctor</td>
<td>3%</td>
</tr>
<tr>
<td>Self-Referral</td>
<td>2%</td>
</tr>
<tr>
<td>Therapist</td>
<td>2%</td>
</tr>
<tr>
<td>Community Nursing Team</td>
<td>2%</td>
</tr>
</tbody>
</table>

District Nursing Team was at the first anniversary event to learn more about the services offered by the Connected Palliative Care team. (Left to right): Clinical Lead for Victoria and Cape Hill Rebecca Vivian, District Nurse Team Nader Charn Sangha for Victoria and CapHill, and Clinical Lead Jerry Nyoni for Sherwood District Nurses.
8. Summary and Future Challenges

Considerable progress has been made since the service began on the 1st April 2016 meeting targets for operational and outcome performance. Patients and families registered with the service are telling us that they have access to an efficient, caring service which delivers the care they are wanting, often in the place of their choice. We have effective mechanisms in place to avoid many unwanted acute hospital admissions towards the end of life, getting care delivered at home when needed and if an alternative venue is requested, arranging this in a timely manner.

Challenges remain in ensuring that every patient and their family are able to engage with sensitive Advance Care Planning, something that evidence suggests will help to support patients and their families to meet their choice about place of care and of death.

There are considerable opportunities to improve the experiences of all local people who reach the end of their lives and the people who care for them regardless of diagnosis or social grouping. Joining the national move to starting positive open conversations about death and dying will help us move towards a culture which sees death as a natural part of life.

To do this we need to look beyond a solely Health Service Model and introduce a Public Health approach to incorporate community development to support the dying, those important to them, and those who are bereaved.

Our objectives for 2017/18 include:

1. Start to develop Public Health approach for wellbeing at the end of life by working with our local government and communities; in partnership with social care organisations, to improve health in the face of life-threatening/life limiting illnesses, caregiving and bereavement.

Partnering with our local communities we would like them to develop their own approaches to death, dying, loss and caring. This will enable community members to identify their unique needs to be actively and independently involved and to take responsibility for the design and implementation of their own end-of-life care policies and practices.

2. For ongoing Connected Palliative Care service development, we will:
   a. Further develop our new therapeutic day hospice at Rowley Regis Hospital, with outreach satellite day hospice clinics across the locality bringing care closer to people’s homes.
   b. Actively ask local bereaved families regardless of whether they have accessed our services about their experiences in order to improve care for all.
   c. Develop a process to record information on all patients with protected characteristics to ensure we are able to see how inclusive we are and use this information to develop strategies for ensuring our services meet the needs of all our community.
   d. Engage further with local GPs and other clinicians involved in caring for people with non-cancer diagnosis to improve recognition and referral of people who would benefit from our services.
   e. Further develop local training of staff across hospital, care home and community settings to be able to provide care and talk about important end of life care issues.

For further information about the service see:

Face Book: https://www.facebook.com/ConnectedPalliativeCare/
Website: https://www.swbh.nhs.uk/services/connected-palliative-care/
Telephone: 01215073611
Twitter: @SwbConnectedPC

References:

SWBH Palliative and End of Life Care Five Year Strategy (2013)

National Ambitions for Palliative and End of Life Care (2015)
http://endoflifeambitions.org.uk/

Public Health Approach to Palliative and End of Life Care: National Council for Palliative Care and Public Health England
http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf

9. Appendix 1: New staff recruitment

<table>
<thead>
<tr>
<th>Existing establishment</th>
<th>SWBH recruitment</th>
<th>Partners recruitment</th>
</tr>
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<tbody>
<tr>
<td>1.6 WTE palliative medicine consultants</td>
<td>1 x band 7 End of life care facilitator</td>
<td>Sandwell Crossroads</td>
</tr>
<tr>
<td>1 WTE band 8b lead Nurse and Head of service</td>
<td>5 x band 6 End of life care facilitators</td>
<td>4 x additional healthcare assistants (working in URT)</td>
</tr>
<tr>
<td>1 x band 5 project facilitator</td>
<td>1 x band 7 palliative care urgent response team leader</td>
<td>Plus additional carers to provide day and night respite.</td>
</tr>
<tr>
<td>1 WTE band 8a lead Nurse</td>
<td>1 WTE band 7 community palliative care specialist nurses</td>
<td>Age Concern Birmingham</td>
</tr>
<tr>
<td>7 WTE band 7 community palliative care specialist nurses</td>
<td>9 x band 6 palliative care urgent response nurses</td>
<td>1 x welfare rights advisor</td>
</tr>
<tr>
<td>5 WTE band 7 hospital palliative care specialist nurses</td>
<td>1 x band 6 occupational therapist</td>
<td>1 x a care coordinator</td>
</tr>
<tr>
<td>3 WTE band 6 palliative care nurses</td>
<td>1.4 band 4 care coordinators</td>
<td>Plus several domestic staff</td>
</tr>
<tr>
<td>0.6 band 7 specialist Occupational therapist</td>
<td>5 x band 2 administrators</td>
<td></td>
</tr>
<tr>
<td>2.85 band 6 Occupational therapists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.85 band 4 therapy support worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 WTE band 3 healthcare assistant</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Plus additional carers to provide day and night respite.
www.twitter.com\SwbConnectedPC
You can also visit our Connect page
connect2.swbh.nhs.uk/palliative-care/