

P-38 ESTABLISHING A PERINATAL PALLIATIVE CARE SERVICE FOR THE WEST MIDLANDS

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Perinatal services include support to both antenatal (pre-birth) referrals and neonatal referrals (generally defined as up to 28 days of age), and this cohort make up a large proportion of childhood deaths. Prior to October 2021 the Paediatric Palliative Care Service (PPCS) at Birmingham Women's & Children's Trust had insufficient resources to sustainably provide specialist perinatal palliative care services. With the addition of a second PPCS consultant with interest and experience in perinatal palliative care, a service has been established and this study reviews this improvement initiative.

Antenatal referral to palliative services offers specialist support to complex birth planning, after death care planning, symptom management planning, and facilitates seamless transitions and continuity across care locations (such as to hospice from maternity services, between fetal medicine to neonatal services and also maternity to children's services). A perinatal palliative care service offers much more than consultations though, with multidisciplinary specialist support available to healthcare services, educational support to related services and attendance at weekly fetal medicine and neonatal service multidisciplinary meetings to provide pre-referral guidance and support. Our service has been able to also provide these diverse elements across the West Midlands.

Improvements seen include significant increases in perinatal referrals with increased uptake of Acorns Hospice support. From 2017 to 2021 Acorns had one to three antenatal referrals per year and in 2022 has already had three antenatal referrals at time of writing in May. PPCS has had a massive increase from five antenatal referrals (2018 to Oct 2021) to 16 (October 2021 to May 2022). We outline the key elements in setting up a perinatal palliative care service and the key improvement outcomes to be considered including a case study highlighting improved experiences of families with a baby with palliative needs. We conclude that the perinatal service has been an important development for the West Midlands and discuss future directions.

P-39 COLLABORATIVE WORKING: HOW AN ADULT AND CHILDREN'S HOSPICE WORK TOGETHER TO PROVIDE HOLISTIC PATIENT CARE BASED ON SHARED EXPERIENCES

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Background In April 2022, St Giles Hospice and Acorns Children's Hospice collaborated to ensure that babies, children and young adults could access the vital day services of Acorns Children's Hospice whilst their building underwent a refurbishment. Together for Short Lives (2016) acknowledges that adult hospices can often be very daunting places for young adults due to the increased number of patients that are seen, many will be at the end of their lives and the hospice environments are very different.

Aim Review learning opportunities of an adult hospice and a children's hospice working alongside each other.

Method A collaborative partnership was formed between the two hospices that enabled Acorns access to patient rooms and office rooms to ensure that patients and their families were able to continue to access respite and end of life support during a six month refurbishment of the Acorn's in-patient unit. To ensure that this was a true collaboration, a working group was set up that consisted of representatives from each hospice to look at how the two hospices could coincide within the same building. Representatives included staff nurses, physiotherapists, directors, catering, volunteers and facilities. Weekly meetings were instigated to look at room requirements, how to embed staff, governance arrangements and communication both internally and externally. The meetings will continue throughout the duration of the collaboration to capture any learning as time progresses.

Results It is hoped that when the six months end in October 2022 that there will be a number of learning points:

- Increased awareness of young adults' needs when transitioning into an adult hospice.
- Review of services to make them more accessible to young adults.
- Greater collaboration between adult and children's hospices.

Conclusion This is an innovative partnership focused solely on maintaining access to in-patient hospice care for children. Review will transform how we design services in the future for transitioning young adults.

P-40 YOUNG PEOPLE AND TRANSITION AT A HOSPICE FOR ADULTS

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Background The hospice recognised a gap in services for patients, relatives and carers aged 18-30 and that services should be more age appropriate (Smith, Mooney, Cable, & Taylor (eds.). Teenage Cancer Trust, 2016). In addition, young people are living longer with life-limiting conditions (Fraser, Gibson-Smith, Jarvis, et al., 2020.) so transition to adult hospice services has become more necessary, which can be a daunting process (Beresford, 2013).

Aim(s) Provide a 3-year National Lottery funded Young Person & Transition Key Worker to support patients, relatives and carers aged 18-30 accessing adult hospice services. The key worker will ensure that the needs of young people are understood, staff have the skills and knowledge to support them effectively and that transition to the adult hospice is a smooth and reassuring process.

Methods The Young Person & Transition Key Worker offers support by:

- Giving young people a voice (National Institute for Health and Care Excellence. [NG43], 2016); using their feedback to shape services.
- Providing age appropriate services and adapting existing ones, where possible, to meet the individual needs of the young person.
- Offering support to relatives and carers aged 18-30.

- Promoting the service to ensure that local agencies are aware of the support available to young people and to allow collaborative work.
- Working with local children's services to create a better transition pathway.

Anticipated results Young people and their families will feel confident to choose hospice services. Services at the hospice will be age appropriate. Transition from children to adult services will be less daunting.

Innovation Although it is understood that the needs of young people differ from the needs of the population usually supported in adult hospices, there are few roles that are specifically designed to support people 18-30 in this setting. A key worker to meet the individual needs of young people is not only unusual but also invaluable in ensuring young people have the best possible experience (Noyes, Pritchard, Rees, et al., 2014).

P-41 TEETERING ON A CLIFF EDGE: TRANSITIONING BETWEEN PAEDIATRIC AND ADULT HOSPICE SERVICES

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Background The transition process from paediatric to adult hospice care is uniquely challenging for young adults living with non-malignant life-limiting conditions as they are often declining in health with increasing dependence on their families for all aspects of care. Many young adults and their families feel that there is nothing for them on leaving paediatric services and that they teeter on a 'cliff edge' with no hope for the future. Without a robust process of transition, the young adults' physical and mental wellbeing may be negatively impacted upon and yet the transition of young adults with complex conditions is not currently a health and social care priority.

A pathway Identifying that there was a need to prioritise transition, Children's Hospices Across Scotland (CHAS) and The Prince & Princess of Wales Hospice (PPWH) worked collaboratively to pilot a Transition Pathway. This involved the development of a categorisation template for the transition caseload with subsequent identification of 12 young adults aged between 19 and 20, all of whom have a non-malignant diagnosis. Over an 18-month period, 4 young adults have fully moved to the adult hospice, 4 continue to remain on both caseloads, 3 have been discharged directly from CHAS with no adult hospice input, and 1 has died.

Conclusions Focus groups for the young adults/families to share their experience of the pilot are planned to enable a full evaluation. However, ahead of these conversations it is recognised that collaborative working is essential to ensure a robust joint approach to transition, supported by: information sharing regarding the differences in services offered (and thereby demystifying what an adult hospice is); open conversation to develop a foundation of trust between the young adult/families and the health care professionals; and the development of an individualised 'at their pace' transition plan to support the health and wellbeing of the young adult and their families moving forward.

P-42 TRANSITIONING TO ADULT CARE – A NEW PROJECT FOR YOUNG ADULTS WITH DUCHENNE MUSCULAR DYSTROPHY

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Over the past three years Wirral Hospice St John's and Claire House Children's Hospice have collaborated on projects aiming to provide continuing care for young adults transitioning from paediatric to adult services. The success of this project has been previously presented; the feedback has been overwhelming positive. This initial cohort was comprised of patients with severe learning difficulties and support for parents was a significant focus.

We now recognise the need to extend this offer to other young adults entering the transition process.

The next phase aims to engage with young adults with Duchenne Muscular Dystrophy (DMD). DMD is a genetic disorder characterised by progressive muscle degeneration typically presenting in childhood. Until recently survival beyond teenage years was unusual, thanks to advances in respiratory care, life expectancy now stretches into the third decade.

Our aim was to engage young adults with DMD in adult palliative care services. We provide physical and psychological support for young adults and their families, as well as offer engagement in advance care planning. We recognise the shift for families, as care becomes more patient rather than family-focused and aim to support young adults as the expectation moves to them taking responsibility for their own care.

This project is ongoing. Four young adults with DMD are engaged in adult palliative care services. These patients have seen consultants initially then linked into dietician, counselling and physiotherapy support as appropriate. Connections made with adult specialist services and when admission to hospital has been required, specialist palliative care has supported. Support has been offered to parents. This has presented challenges for adult services in terms of equipment/services offered; we continue to adjust to the requirements of younger patients.

There is significant unmet need for young adults facing the daunting prospect of leaving paediatric services, this project has shown that palliative care services can work together to improve this transition.

P-43 ABSTRACT WITHDRAWN

P-44 TRANSFORMING CARE FOR YOUNG ADULTS WITH COMPLEX AND LIFE-LIMITING CONDITIONS

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Background More young people with complex life-limiting conditions are living into adulthood, generating greater demand for appropriate care (Fraser, Gibson-Smith, Jarvis, et al., 2021. *Palliat Med.* 35:1641). We implemented Project