

Family Counsellor (FC) for Palliative Children and Young People in Collaboration with Paediatric Palliative Care (PPC) and Ty Cymorth Bereavement Service. Two Year Pilot Study

HDdUHB Charitable Funds Committee

28th November 2022

Angharad Davies Childrens Community Lead Nurse

Rebecca McDonald CNS Paediatric Palliative Care



TIMELINE

- 8/07/2021 – Job description gone through job matching and consistency checking for banding. Band 6 post agreed
- 27/09/2021 – Angharad Davies, Childrens Community Lead Nurse and Rebecca McDonald, Clinical Nurse Specialist Paediatric Palliative Care attended HDdUHB Charitable Funds Committee to request funding for a Family Counsellor. The Committee agreed to fund a 2 year pilot.
- 5/11/2021 – Vacancy advertised live on Trac (external advert)
- 18/11/2021 – Discussions as MDT held with Value Based Health Care team
- 21/11/2021 – Job vacancy closes on Trac
- 23/11/2021 – Shortlisting - 5 applicants applied; 3 shortlisted for interview
- 30/11/2021– Virtual interviews held. 1 successful candidate recruited into post
- 09/02/2022 - Family Counsellor commenced role



What have we done so far?

- Successfully recruited Penny Skyrme Family Counsellor for Palliative Children and Young People (BACP accredited).
- Embedded the FC into the PPC Team.
- Set up working group to look at referral process, audit and other documentation to support the FC in her role.
- Met with Value Based Health Care to look at how to achieve measurable outcomes. No one tool meets criteria. FC utilising 4 tools to support outcomes: Children, Young People (CYP) Core distress and risk assessment, core 10 adult distress and suicide risk assessment, GAD -7 Anxiety (General Anxiety Score Sheet), PHQ-9 (Patient health questionnaire regarding depression).
- Excel document created by FC to record numerical data/hours etc.
- Governance in place.
- Referrals made to FC by PPC Team.
- FC now established, building relationships with CYP and their families and working well within her role.

Achievements to date

- Family Counsellor is now fully embedded into the Paediatric Palliative Care Team/Community Children's Nursing Service
- Family Counsellor receiving regular Clinical supervision via Ty Cymorth Bereavement Service.
- Monthly meetings with PPC Team/Ty Cymorth initiated now running bimonthly, aim to go three monthly.
- CYP and wider family members have been referred for ongoing counselling support. No waiting time.
- Networking and partnership working enhanced with third sector providers.
- FC working closely with local children's hospice therapies team and has seen parents/siblings who have been sat on waiting lists with hospice provider.
- Joint working with FC and family support team in hospice has been initiated increasing hospice capacity for other CYP/families, also enabling FC to be creative and flexible with own caseload demand and capacity within the 22.5 contracted hours
- Weekly online boys group set up for 4 boys with similar health needs, breaking down barriers of isolation.
- In progress of working towards establishing a Mum's online support group.
- FC nominated by family for Outstanding Clinician Care Award for this year's SOFT UK Annual Awards 2022. SOFT UK offers help and support to families affected by trisomy 13 & 18. This award gives our community a voice to nominate someone who has been particularly supportive and gone the extra mile for them in their journey.
- Spreading Sunbeams Team Finalist in RCNI Awards. Bereavement support from FC has been pivotal in conjunction with bereavement midwife and PPC Team for one of these perinatal palliative care referrals. This counselling support is ongoing with a bereaved mother.
- Patient experience story/video undertaken with Clinical Nurse Specialist and FC with bereaved mother. This is now being used for learning and education purposes.

Patient feedback so far...

A mother's quote:

'The family counsellor has been crucial in the aftermath of losing my son. Having constant and regular appointments has been helpful'. I am so thankful this service is available to me'.

Penny is easy to talk to and provided a safe and non-judgmental environment to discuss all the issues surrounding palliative care and the effect this has had on family life.

The service would benefit from a designated room at the hospital as I know scheduling a room can be tricky for people who would rather not be seen at home or over skype.

Access to the service is not flexible enough. Families need to be able to access it in crisis and out of hours

Quote from a child:

Penny is fun. When asked if there was any improvements to service to be made one child quoted, I would like to see more games included in my session'.

Brief Overview of Data

- Referrals made to FC to date: 13 in total
- 4x CYP with life limiting conditions on PPC caseload who are cognitively able
- 2x fathers of CYP on caseload for anticipatory grief support, resilience training/coping strategies
- 3x mothers of CYP on PPC caseload
- 2x siblings of CYP on PPC caseload
- 2x mothers on PPC caseload recently bereaved receiving bereavement counselling (ongoing)
- Online virtual group sessions with the boys (7 sessions held to date/ongoing)

Counselling Sessions Undertaken So Far...

- 44 individual sessions offered to CYP
- 7 group sessions delivered to CYP
- 49 sessions offered to wider family

Early evidence to date suggests that embedding the Family Counsellor within the team is increasing uptake for anticipatory grief support.

Total counselling sessions for wider family

