



**PWYLLGOR CRONFA ELUSENNOL
CHARITABLE FUNDS COMMITTEE**

DYDDIAD Y CYFARFOD: DATE OF MEETING:	27 September 2021
TEITL YR ADRODDIAD: TITLE OF REPORT:	Family Counsellor Proposal for Paediatric Palliative Care Across the Three Counties of Hywel Dda University Health Board
CYFARWYDDWR ARWEINIOL: LEAD DIRECTOR:	Lisa Humphrey, Interim General Manager, Women and Children's Directorate Andrew Carruthers, Director of Operations
SWYDDOG ADRODD: REPORTING OFFICER:	Jayne Thomas, Paediatric Palliative Care Clinical Nurse Specialist Angharad Davies, Senior Nurse Manager Community

Pwrpas yr Adroddiad (dewiswch fel yn addas)

Purpose of the Report (select as appropriate)

Ar Gyfer Penderfyniad/For Decision

ADRODDIAD SCAA

SBAR REPORT

Sefyllfa / Situation

There is currently limited access to psychological and counselling support within Hywel Dda University Health Board (HDdUHB) to meet the mental health, emotional health and wellbeing of children and young people (CYP) and their families who are living with a life limiting or life threatening diagnosis. Due to the current fragmented county based framework, there is a lack of equity and cohesiveness, which can lead to confusion for families and professionals on how and where to access timely family focused counselling support. As a result of the limited resource available within the service, waiting times can often be lengthy. This also applies to local charities who serve limited numbers within clearly defined geographical areas within HDdUHB.

This report requests that the Charitable Funds Committee considers funding a pilot project for a family counsellor (FC) over a period of twenty four months. This would enable the necessary scoping, ongoing evaluation and outcomes to measure the need and effectiveness of interventions, and improvement in health outcomes. This would inform future service design, provision, and support any commitment made by the Health Board and/or the Charitable Funds Committee, towards an ongoing sustainable service, including any associated benefits.

Cefndir / Background

Counselling and psychological support is currently provided on a need basis from various sources within HDdUHB. However, services are inequitable across the three counties with CYP and their families having to meet each service's individual referral criteria along with significant delays between referral and treatment times. In most cases, time is not on their side as the unavoidable prospect of dying and eventually death could be a matter of days or weeks. It is unacceptable for any child or young person who has a life limiting diagnosis, and their family, to wait to be accepted by a service, which inevitably results in their needs being unmet. This consequently results in a further decline in their mental health and well-being until a crisis point is reached, which creates further dependence on both primary and secondary care services.

Throughout a CYP illness trajectory, the CYP, parents or carers, and siblings may experience relationship difficulties, emotional and psychological anxiety, and mental health issues to a point of crisis management. A FC embedded into the Paediatric Palliative Team would be able to undertake preventative measures, which would have a direct impact on the CYP, parents or carers, and sibling's coping skills, resilience and quality of life.

CYP and their families may experience high levels of stress, anxiety or low mood, which is known to influence adherence to management and treatment. This can often lead to the creation of intense pressures, worsening of symptoms for the CYP, relationship difficulties and depression. Once families are exposed to these pressures over time, professionals witness increased dependency and attendance at primary care, in addition to unscheduled care attendance/admission to Emergency and Paediatric Departments. A lack of resilience and coping strategies within a family unit can lead to increased length of stay and delayed discharge, which would have financial implications for both HDdUHB and tertiary centres.

Issues of Significance to the Health Board

Inevitably, dying is something we all share; the impact of symptoms, the effects of treatment and the value we place on quality of life will be different for each of us. HDdUHB's Palliative Care Strategy 2020-2040 provides structure and clarity, setting out where 'we have been', 'where we are, 'where we are going' and 'where we want to be'. The Palliative Care Family Counsellor pilot project has the potential to facilitate the HDdUHB Palliative Care Strategy 2020-2040 collective vision for a true partnership and person-centred approach to palliative care across HDdUHB. This will enable the production of an efficient, sustainable, quality service inclusive of all age groups. The need for a palliative care FC within Paediatrics has been highlighted in the bi-monthly meetings of the Hywel Dda Palliative Care Strategic Group, who lead on the HDdUHB Palliative Care Strategy 2020-2040. At present, there are insufficient funds for the project due to the presence of already conflicting priorities within the HDdUHB adult palliative care service.

National and Local Objectives

The National Institute for Health and Care Excellence (NICE 2016) recommend the need for psychology support to be embedded into the practice of multi-disciplinary teams, stating that palliative CYP and their parents or carers require support and expert psychological interventions to help with their distress, coping mechanisms and resilience.

In 2017, the Welsh Government (WG) published the Palliative and End of Life Delivery Plan, which provides a framework for service development and delivery. The seven delivery themes highlight that children, young people and adults should have access to high quality palliative care wherever they live, regardless of their underlying disease or disability. The seven themes incorporate:

- Supporting Living and Dying Well
- Detecting and Identifying Patients Early
- Delivering Fast Effective Care
- End of Life Care
- Reducing the Distress of Terminal Illness for Patients and their Families
- Improving Information
- Targeting Research and Education

Priority two of the HDdUHB Palliative Care Strategy 2020-2040 states that, *the care needs to be seamless and integrated, across all services from diagnosis of a life-limiting condition (LLC) through to death and bereavement.*

Funding

To date, all avenues of internal funding within the Health Board's Adult and Children Bereavement Service, Palliative Care Group, and the Women and Children's Directorate have been extensively explored. Due to the current revenue position and priorities placed upon these services, the project steering group has been unable to allocate the required resource for this much needed post due it being outside of the scope of statutory provision. The role of the FC post is a creative and sustainable post, which could be considered suitable for the application for charitable funding.

Additionally, avenues of external funding have been continually revisited and Service Level Agreements (SLA) have been extensively explored. However, due to disparity in access to this provision across the three counties, the project steering group's preference is to embed the post of FC within the Paediatric Palliative Care Team and Bereavement Service. This option would enable the best possible outcomes with regards to service user engagement and needs. Once the FC has been embedded within the service, there is potential for the Health Board to consider an SLA for future long term maintenance of the role.

Asesiad / Assessment

The project will aim to facilitate and provide psychological support to meet the mental, emotional health and well-being needs of CYP and their families who are living with a life limiting or life threatening diagnosis. The project will reduce the risk of crisis management through assessment and early intervention, and identify potential resources within HDdUHB, the third sector and charities to promote positive adjustments and resilience.

The FC will not be a 'stand-alone' practitioner within the Paediatric Palliative Care Team. The operational management of the FC will sit within the infrastructure of the Health Board's Bereavement Services. The FC caseload will be managed by the Paediatric Palliative Care Service. This will facilitate the palliative care team to establish the CYP and parental trust in regard to the availability of a FC when/if required, as they face the uncertainty and unpredictability of death and dying in the future. User engagement will be critical and therefore, the FC's role within the team will provide some assurance in terms of increased user acceptance of the service, the attainment of positive health outcomes, and overall cost effectiveness.

Managing clinical uncertainty, reducing suffering and supporting complex decision making are qualities and traits associated with effective palliative care and are essential in supporting a pandemic. The risk of child /domestic abuse, social isolation, fear of contagion, and loss of family members and friends is compounded by the distress caused by loss of income and often employment for their parents. Families from lower socioeconomic backgrounds are typically more susceptible to: financial hardship; caring for at least one life limited child as they juggle to meet the complex healthcare needs of the child; marital relationships; home-schooling; domestic tasks; and household bills. Palliative CYP are highly vulnerable to the psychosocial implications of the pandemic as they are experiencing unprecedented changes to their sense of security and normality. This adds to the fear, anxiety and sadness that already exists within families. A failure to take CYP and families' mental health and emotional wellbeing seriously will lead to long term social and health care economic costs. In a pandemic, isolation and social distancing procedures can impact negatively on holistic care, which requires services to be proactive in their delivery and to improve remote access to services. Early prevention and support for these CYP and families is key to improving the delivery of safe, sustainable and effective care, which in turn will result in positive measurable outcomes.

Holistic assessment of the whole family is vital in the role of the FC. Working closely with local community organisations and NHS charities is fundamental in the provision of holistic assessment when considering the needs and support that may be required in the family unit. Signposting to relevant services with the appropriate skills and expertise is essential to the role's success. Partnership working between CYP and families, and primary care and third sector providers, is required in order to meet different needs and any ongoing needs that may be identified as part of reassessment and the discharge planning process. Signposting to services therefore requires a coordinated approach. A few examples of services in the community that the FC may refer onto or work closely with as the needs of CYP and family members are identified or change over time, include services such as advocacy, MIND, the Mental Health Foundation, and young carers. Further examples include linking into national charities utilised by the NHS such as the Teenage Cancer Trust and CLIC Sargent, and local cancer and bereavement charities such as Paul Satori, Ty Hafan Children's Hospice and Sandy Bear Children's Bereavement Charity. These charities support the process by offering opportunities above and beyond that which the NHS can provide such as days out, complementary therapies, young carer support, and parent and sibling groups.

The evidence base suggests that patient care supported by the right organisational structure of an interdisciplinary team can have a positive influence on quality and effectiveness of care. Integrated within the Paediatric Palliative Care Team, the FC would work closely with the Paediatric Palliative Care Play Specialist. Working in partnership will enhance the delivery of care, either within the home, virtually, or by linking into community services such as social care and education. Increased attendance in education settings and engagement with social care services are also widely documented as being vital components to delivering positive outcomes for these families.

The impact of the pandemic on certain groups such as palliative CYP and families has directly impacted upon the availability of services. A FC embedded into the Paediatric Palliative Care Team can undertake preventative measures with palliative CYP and families, which can have a direct impact on their mental health and wellbeing, thereby preventing crisis interventions, reducing primary care contacts, minimising admission to secondary and tertiary care services and reducing length of stay in hospital.

Benefits

The benefits of the FC role are summarised below:

- A FC who is integrated within the paediatric palliative care team /bereavement service will alleviate the potential stigma associated with receiving psychological support and improve engagement with the service.
- Improve the probability of positive health outcomes for CYP and families in the short, medium and long term by enhancing the physical, mental, and emotional health and wellbeing, of CYP and their families, symptoms of which have been exacerbated by the pandemic.
- Enable early access to psychological support, which will minimise and/or prevent any anxiety, distress and unnecessary suffering.
- Potential to reduce long term social and health care economic costs.
- Maximising resilience, enhance coping skills and enabling CYP and families to develop strategies to manage anxiety and stress, leading to overall improvements in their quality of life.
- Improvements to patient and family experience.
- Access to the existing infrastructure of the operations management within the Bereavement Service, ensuring appropriateness and accessibility of clinical supervision. The administration of the service will be accommodated at Ty Cymorth.
- Improve research and enhance the current evidence base.

- Facilitate and improve educational provision to staff.

Risks

If the pilot project is not funded, there is a risk of:

- An increase in psychological and mental health conditions of CYP and their families with a life limiting/life threatening condition.
- Increased risk of CYP and their families/carers reaching crisis point.
- An increase in primary care contacts and admission to secondary and tertiary care services for CYP and families.
- Increased social and health care costs.
- Continued lack of availability of appropriate psychological and counselling support for CYP, their families or carers.
- The patient experience would be significantly and negatively affected by the lack of psychological and counselling support.
- Poor access to education and training provision for staff who are caring for and supporting CYP, their families and carers, who experience psychological distress around anticipatory grief.
- Sustaining the inability to improve the research and evidence base in this area.

Governance

The project group will establish a work plan to ensure the project is clearly aligned to the strategic aims and business objectives of the Women and Children’s Directorate, within robust governance arrangements, i.e. performance of the project, cost escalation, delay or significant change to objectives, or other high risks. The project reporting officer will hold accountability to alert the Health Board, with a recommendation from the project steering group members on action to take.

The overall objective of the project is to measure the impact of the support provided by a dedicated FC to CYP with a life limiting condition in relation to positive health outcomes, utilising both qualitative and quantitative data. A recognised measurement tool will be utilised by the FC with support from the Bereavement Service Manager and Project Steering Group. The project data can provide evidence to support the recognition of psychological management required, the effectiveness of interventions within palliative family focused counselling therapy, and outcomes. The present and future care requirements can be explored, communicated and further developed with CYP’s parents, siblings and multidisciplinary team members within the community team.

Costings

Family Counsellor	Band	Hours	Duration	Cost
Accredited with training and qualification with children	6	0.6 WTE	24months	£25,488 mid point per annum with no requirement for enhancements Total cost for 24 months: £50,976

Set up costs:

- Smartphone and case, with remote access to e-mail, intranet and files: **£225.00**
- Standard 14” Dell Laptop & Case: **£740.00**
- Remote Access Token (RSA Secure-ID token): **£35.00**

- Hardware: Encrypted Memory Stick **£20.00**

Total: **£1,020.00**

Travel costs: To support visiting across HDdUHB, i.e. home visits, educational visits etc.
Total: Approx. £2000 per annum.

Total funding requested: £55,996 over a 2-year period (£28,508 year 1, £27,488 year 2).

The following charitable funds will be utilised to support this application:

Fund code	Fund name	Fund balance £ M5 2021/22	Value of contribution £
T606	Paediatric Palliative Care (Play Service)	12,533.97	£12,000
T780	Carmarthenshire Children's Services	87,631.29	£27,000
T807	Ceredigion Children's Services General	17,654.62	£10,000
T921	Pembrokeshire Children's Services General	3,693.58	£996.00
T922	Pembrokeshire Children's Services Children's Wards	13,220.00	£6,000

The above funding requests will be subject to change as the Paediatric Palliative Care Service is committed to continue to explore all other avenues of funding. The Paediatric Palliative Care Team is currently in collaboration with Charitable Funds Officers to launch a specific campaign to raise further funds for the service. Substantive funding for this role will also be considered and/or reflected within the Directorate's Integrated Medium Term Plan (IMTP) as the pilot progresses.

Exit Strategy

CYP and families' consent will be sought prior to any referral to the FC. As part of the consenting process, written guidance will be provided explaining that the FC role will be a pilot project over a period of twenty four months. Recommendations will be made near the conclusion of the twenty four month project, in a timely way, to consider service measures, e.g. a cease on any new referrals in advance of the end of the pilot. If the needs of the CYP or their families change, they will be signposted to the most appropriate service within primary care, secondary care, or third sector provision. Furthermore, if additional funding is unable to be sourced following the end of the pilot, Ty Cymorth Bereavement Service will honour and oversee any children and families who remain active on the FC caseload who are assessed as requiring ongoing support and intervention.

Argymhelliad / Recommendation

The Charitable Funds Committee is requested to consider funding of £55,996 for a part time family counsellor (0.6wte) for a twenty four month pilot project, to facilitate and provide psychological support to meet the mental and emotional health needs and well-being of children and young people and their families living with a life limiting or life threatening diagnosis.

Amcanion: (rhaid cwblhau)

Objectives: (must be completed)

Committee ToR Reference:

Cyfeirnod Cylch Gorchwyl y Pwyllgor:

4.20 The following thresholds are approved in the Charitable Funds Procedure:

"Expenditure less than £5,000 shall only need

	<p><i>approval by the nominated fund manager. All expenditure in excess of £5,000 and up to £25,000 will require the approval of the Deputy Director of Operations on behalf of the Charitable Funds Operations Sub-Committee. All expenditure in excess of £25,000 and up to £50,000 will require the approval of an Executive Director. Expenditure in excess of £50,000 will require the approval of the Charitable Funds Committee”. Expenditure over £100,000 will require the approval of the Corporate Trustee”.</i></p> <p>4.22 It also states that the following expenditure types require Committee approval:</p> <ul style="list-style-type: none"> • <i>“Research & development expenditure”</i> • <i>“Pay expenditure”</i> • <i>“Training including conferences/seminars etc requiring attendance of participants outside the UK”.</i>
<p>Cyfeirnod Cofrestr Risg Datix a Sgôr Cyfredol: Datix Risk Register Reference and Score:</p>	<p>The evidence and the concern raised by CYP, their families and professionals in the issues highlighted in this report in the provision of timely family counselling for paediatric palliative care is currently being gathered and will be added to the Women & Children’s Directorate Risk Register.</p>
<p>Safon(au) Gofal ac Iechyd: Health and Care Standard(s):</p>	<p>3.1 Safe and Clinically Effective Care 3.2 Communicating Effectively 3.3 Quality Improvement, Research and Innovation 5. Timely Care</p>
<p>Amcanion Strategol y BIP: UHB Strategic Objectives:</p>	<p>5. Deliver, as a minimum requirement, outcome and delivery framework work targets and specifically eliminate the need for unnecessary travel & waiting times, as well as return the organisation to a sound financial footing over the lifetime of this plan</p> <ol style="list-style-type: none"> 1. Starting and developing well 2. Living and working well. 4. Improve the productivity and quality of our services using the principles of prudent health care and the opportunities to innovate and work with partners.
<p>Amcanion Llesiant BIP: UHB Well-being Objectives: Hyperlink to HDdUHB Well-being Objectives Annual Report 2018-2019</p>	<p>2. Develop a skilled and flexible workforce to meet the changing needs of the modern NHS 8. Transform our communities through collaboration with people, communities and partners 4. Improve Population Health through prevention and early intervention, supporting people to live happy and healthy lives</p>

**Gwybodaeth Ychwanegol:
Further Information:**

Ar sail tystiolaeth: Evidence Base:	Appointment of a FC will provide palliative CYP and their parents and siblings with a means of communication, which would enable them to give voice to their thoughts, emotions and experience related to the CYP's life shortening condition as each member of the family strive for normality and independence within the known prospect of dying and death.
Rhestr Termau: Glossary of Terms:	Included within the body of the report.
Partïon / Pwyllgorau â ymgynhorwyd ymlaen llaw y Pwyllgor Cronfa Elusennol: Parties / Committees consulted prior to Charitable Funds Committee:	Women and Children's Directorate Nurse Community Children's Senior Nurse and Service Delivery Manager HDdUHB End of Life Board Committee Head of HDdUHB Charities

Effaith: (rhaid cwblhau) Impact: (must be completed)	
Ariannol / Gwerth am Arian: Financial / Service:	<p>Future considerations:</p> <ul style="list-style-type: none"> • A repeat application to charitable funds, should the project demonstrate that an extension on the scoping period would be beneficial. • A repeat application to charitable funds to fund an ongoing FC validated by project data and outcomes. • Application for, and consideration of, mainstream HDdUHB funded provision of a FC, validated by project data and outcomes. • To explore funding streams that may become available in the future, i.e. Integrated Care Fund
Ansawdd / Gofal Claf: Quality / Patient Care:	<p>Whilst providing a pilot service, the project will also be a scoping exercise with ongoing and concurrent evaluation to measure the need that exists and the effectiveness of interventions.</p> <p>The FC and Project Steering Group will be responsible for quantitative and qualitative data collection and outcomes: Number of referrals, number of contacts with FC, contacts made with primary care, admissions to secondary / tertiary care and the level of counselling that was provided to capture the service need, observing through the life of the project any trends, i.e. does the need for higher level counselling decrease as the psychological support and skills of the practitioners involved with palliative CYP increase.</p> <p>Qualitative measures/outcomes: Service user record of experience measures to be collected via engagement survey once discharged from the FC to include CYP, family member, carer, sibling affected by a LLC.</p>
Gweithlu: Workforce:	The FC, in conjunction with the Paediatric Palliative Team, will provide training in the development of psychological skills for staff members in their encounters with the more complex palliative children and their families to facilitate staff sustainability and resilience.

	A resilience and job satisfaction questionnaire will be undertaken for the workforce at the start and end of the FC pilot project.
Risg: Risk:	Any children or adults who present with self-harm or suicidal ideation should be immediately directed through the mental health care pathway.
Cyfreithiol: Legal:	Health Board standards will be followed. As this is a pilot project over a period of twenty four months, a legal challenge would be unlikely.
Enw Da: Reputational:	There remains a lack of equity and cohesiveness, with fragmentation, gaps and confusion experienced by families and professionals on how and where to access timely family focused counselling support for palliative and end of life children in the three counties of HDdUHB. This also applies to charities who serve limited numbers in clearly defined geographical areas within HDdUHB. The FC pilot project will reduce the risk of crisis management through assessment, early intervention and identification of available potential resources within HDdUHB, the third sector and charities to promote positive adjustments and resilience.
Gyfrinachedd: Privacy:	The FC post holder will process patient data within the existing framework of the Paediatric Palliative Care and Bereavement Service, patient clinical databases and within HDdUHB's existing information governance framework.
Cydraddoldeb: Equality:	The project is available to all complex CYP, and their families, with a diagnosis of a life limiting/life threatening condition who are on the HDdUHB Paediatric Palliative Care caseload during the two year FC pilot project.