

PWYLLGOR CRONFA ELUSENNOL CHARITABLE FUNDS COMMITTEE

DYDDIAD Y CYFARFOD: DATE OF MEETING:	26 September 2023
TEITL YR ADRODDIAD: TITLE OF REPORT:	“Heads Up!” Initiative – Cancer Services Hair Loss Support
CYFARWYDDWR ARWEINIOL: LEAD DIRECTOR:	Mr Andrew Carruthers, Director of Operations
SWYDDOG ADRODD: REPORTING OFFICER:	Mr Keith Jones, Director of Secondary Care Ms Gina Beard, Lead Cancer Nurse

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

This paper presents a proposal for Hywel Dda University Health Board (HDdUHB) to be the first Health Board in Wales to improve the patient experience of cancer treatment related hair loss.

The current statutory NHS provision for chemotherapy related hair loss consists of:

1. A duty to inform patients that medication/treatment will cause hair loss;
2. Providing a £90 voucher towards the purchase of one wig.

There have never been any local support services available to patients across the (HDdUHB) region that have provided a holistic approach to understanding hair loss. There are many ways in which patients can be empowered to help themselves during hair loss related to cancer treatment. However, they need the skills and information to do so. Cancer nurses and hairdressers have limited training on the process and impact of treatment related hair loss. This can mean that advice given to patients can be basic, inconsistent and potentially not evidence based.

The Charitable Funds Committee (CFC) is asked to approve £165,000 of cancer services charitable funds to provide an expert, person centred, holistic hair loss service for patients. This service will bring together healthcare professionals and haircare professionals from our local communities to empower patients with the knowledge and products they need to manage their hair loss journey with dignity and choice.

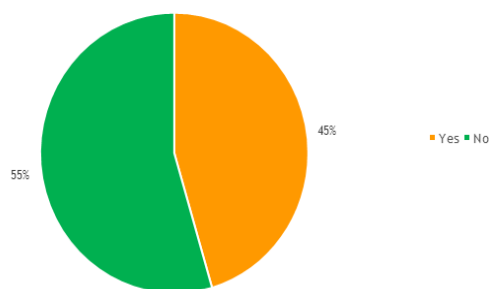
Cefndir / Background

A cancer diagnosis brings with it a great deal of anxiety and fear of the unknown challenges ahead. The additional emotional and life changing experience of hair loss at such a time is therefore particularly complex.

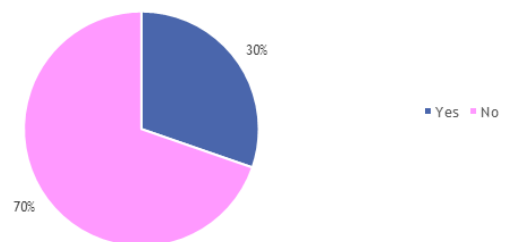
- 70% of female patients who select a wig from the NHS provider only wear their wig 20-30% of the time. This means that they need other head coverings such as a scarf or headwear with fake fringe or other option made available (source: Cancer Hair Care).
- Many patients are not happy with the options provided by the wig supplier.
- The majority of patients find the actual transition into a wig difficult.
- Patients whose faith or cultural beliefs (e.g. Muslim) do not allow the wearing of a wig are not provided with other options.
- Many patients are not offered the opportunity to have their wig customised (cut to suit their face).
- Patient feedback indicates that patients need multiple opportunities to be offered a wig as an option.
- Patients with Afro and Asian hair types do not feel confident that their hair type will be represented by the current wig provision.
- Patients with smaller heads and under the age of 18 years can struggle to find a suitable provision.
- Patients report being 'up sold' to a higher price wig and or additional products by wig suppliers.
- Patients are told incorrect information by some wig suppliers about topics such as scalp cooling, new hair growth, brow and lash care etc.
- Patients do not feel adequately informed about after care of their wig.
- Some patients cannot afford to make a contribution towards the cost of a suitable wig.
- Many patients have to travel long distances to seek a wig provider.
- Not all suppliers provide appropriate access e.g. wheelchair access or privacy.
- Vulnerable patients with additional needs report not being able to access services.
- Cancer healthcare professionals, wig suppliers and hairdressers confirm that they feel uneducated around the subject of cancer treatment related hair loss.

In early 2023, a patient experience questionnaire was sent out to patients receiving chemotherapy at each HDdUHB site to understand their current experience. 66 responses were received:

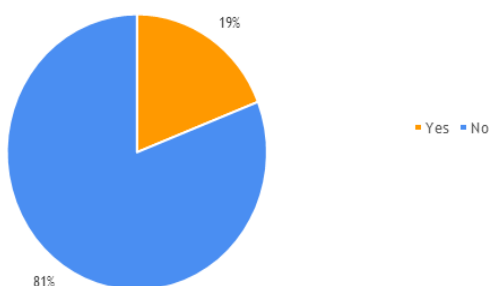
Percentage of patients who were informed about hair cutting and what was appropriate to do



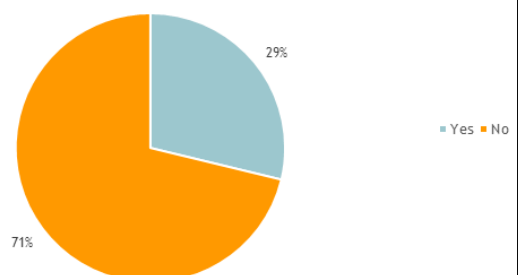
Percentage of patients who had access to a hairdresser who was knowledgeable about scalp care during their treatment



Percentage of patients who had a knowledgeable hairdresser to guide them through the process



Percentage of patients who had access to a hairdresser who could advise them about new hair growth after treatment



Comments received from patients:

Question: Please tell us anything else about your hair loss journey below:

- *It is very distressing to lose your hair because you stop looking like you, yet another part of you has to let go of. My kids did not want me to cut my hair off. I had no information about how to cover up lashes and eyebrow loss and that has been quite distressing too.*
- **Not much help.**
- *I would have liked more information regarding wig fitting.*
- **It was devastating and I hid from people so they did not see my bald head. Spent a fortune on hats to hide my head. Now I am totally comfortable and love ♥️ myself. My hair is gradually growing white It was brown before. Wonderful.**
- *I used my own hairdresser and made my own decision to cut my hair shorter. No information was provided. Who would have provided this?*
- **I don't mind losing my hair but not too keen on wearing a wig, at the moment anyway. I prefer turbans, bandanas, headscarves.**
- *I was told several times that I could get a wig through the NHS however each and every time that was all I got, to be told I could get a wig. No explanation was given as to how this was possible or where to go or how it was a voucher to get money off a wig you had to seek out yourself. I ended up doing all that work myself and showed up at the wig shop empty handed, no voucher, nothing. Luckily the shop assistant was able to call my Chemo ward and get the number necessary from my 'voucher' and I didn't have to go and get it from the hospital.*
- **Very grateful for NHS voucher but have had to pay considerably more for decent quality wig. That aside, it's made a huge difference in terms of enabling me to feel 'normal' through my cancer journey.**

Asesiad / Assessment

The "Heads Up!" hair loss support initiative has been developed using the experiences of our patients as a springboard for change and innovation to promote independence, dignity and choice for people who experience cancer treatment related hair loss.

Pembrokeshire Pilot Project, May to September 2023

The concept of the "Heads Up!" initiative has been tested in recent months across Pembrokeshire. The pilot was delivered by the Cancer Hair Care service under the umbrella of registered charity Caring Hair and funded by the local Withybush Cancer Day Unit Appeal charity (£5,000) with in-kind match-funding provided by the Caring Hair charity (£6,886).

Over the four-month period, hair loss experts from the Cancer Hair Care service visited Pembrokeshire twice, for four days in total. The pilot ends on 20 September 2023 and at the time of writing (07-09-2023) there have been **314 "touchpoints"** that include:

- Nurse/cancer support professionals contact and training opportunities.
- Contact with local hairdressers through a community outreach event.

- Patient consultations in person or remote (workshop on Zoom and Cancer Hair Care helpdesk) covering topics such as scalp care, advice on regrowth, cutting new growth, colouring new growth, using hair care products such as fringes and head scarfs.
- “Ward round” support in Withybush Hospital (WGH) Chemotherapy Day Unit by cancer haircare professionals (with patient consent).
- Hair loss support packs (including free headwear, lashes etc), printed resources and signposting to support networks for all patients who had contact.

The pilot was expected to reach at least 340 touchpoints at a cost per head (patient/nurse/hairstylist) of £32.56. Delivery to date indicates that the total number of touchpoints will be higher than predicted.

Patient stories and case studies will be presented to the CFC during the September 2023 meeting.

Feedback received to date from staff on the pilot has included:

- *Very informative education session. Jasmin was lovely with the patients and the feedback received was that if she hadn't have approached them some patients wouldn't have had the courage to ask.*
- ***Very informative, Jasmin taught me lots I didn't realise I didn't know. Very informative, fun and engaging.***
- *Very good education session, everything was explained in detail and pitched at the perfect level for all to understand, very clear and interesting.*
- ***Really good education session, especially for me as a new member of staff, I found it very informative and relevant.***
- *It was great to meet Jasmin, she is really lovely, certainly the right person in the right job. The education session was excellent. The patient feedback I had was incredibly positive. I witnessed her when she was giving one to one patient consultations and her bedside manner was fabulous. Her visit had a positive impact on patients and staff.*

The Cancer Hair Care service and Caring Hair Charity

Cancer Hair Care is a service delivered by the UK's leading hair loss support charity Caring Hair (registered charity number 1145258). Founded in 2012 by Jasmin Julia Gupta, an NHS nurse educator and advisor, the charity has a successful track record of providing expert advice and support on all aspects of hair loss, hair loss prevention (scalp cooling) and hair care, before, during and after cancer treatments.

Caring Hair delivers services on behalf of a large number of English NHS trusts including University College London Hospitals NHS Foundation Trust, Guy's and St Thomas' NHS Foundation Trust and Great Ormond Street Hospital Trust.

Our proposal

The proposal is to build upon the success of the Pembrokeshire pilot project and extend the “Heads Up!” initiative across the whole of HDdUHB with the aim of improving the patient experience of cancer treatment related hair loss. HDdUHB would be the first health board in Wales to deliver a service of this nature.

The CFC is asked to approve £165,000 of cancer services charitable funds to provide an expert, person centred, holistic hair loss service for patients over a two-year period. This service will bring together healthcare professionals and haircare professionals from our local communities to empower patients with the knowledge and products they need to manage their hair loss journey with dignity and choice.

Professional support

The initiative will provide local healthcare professionals and local hairdressers across the HDdUHB region with training on the wider issues of treatment related hair loss such as:

- How and why hair loss occurs
- Scalp cooling
- Hair regrowth advice and when to colour new hair growth
- Diversity
- Afro hair
- Myth busting
- Technical facts about the difference between chemotherapy induced alopecia and other treatment related hair loss issues e.g. radiotherapy hair loss
- Support for men
- Talking to children
- Up-to-Date wig information

Patient support

The initiative will provide patients with access and specialist advice. Whilst a wig is often perceived (by patients and healthcare professionals) to be the answer to hair loss in fact a wig is only one of many options. For many a wig is not the answer to their hair loss issues.

The initiative will provide the patient with easy access to specific, caring, helpful, independent, vital information and guidance about hair loss. This service offers a full range of specialist supportive services that without funding will not be available to benefit the patient.

A cancer nurse, even with additional training in hair loss, is unlikely to be able to support patients with the in-depth information they require. Cancer nurses are not hair loss specialists or have specialist hairdressing knowledge.

The entire service would be free at point of access to the patients offering geographical and affordable access. Many HDdUHB patients live in rural areas with a lack of travel available to them and/or fall into cancer treatment related financial poverty. Items such as free support packs containing headwear, scalp cooling items, skin coloured wig caps will offer direct dignity to someone who otherwise could not afford it. The service aims to be on site at the appropriate hospitals and available within the local community as well as remotely.

The service will ensure that patients have access to holistic support throughout their hair loss journey and that hair loss is taken seriously. The service would encompass every stage of cancer treatment and hair loss and new growth journey. This helps patients to move forward post treatment.

The service will ensure that access to appropriate information about hair loss is suitable for all people, their hair type, ethnicity and how they identify themselves for example Black, Asian and Minority Ethnic (BAME) and lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual (LGBTQI+).

The service would be available to any person in need of cancer treatment related support in hair loss prevention, hair thinning, hair loss or hair care guidance including loss of body and facial hair. Self-help and outreach services would be available for those who cannot attend face to face.

Extended support can be provided to anyone caring for a patient. Products that facilitate conversations with children, for example our hair loss dolls and children's activity packs help patients explain hair loss to young children in the family.

Reach and Delivery Costs

The "Heads Up!" initiative is expected to reach at least 6,655 touchpoints over the two-year period at a cost per head (patient/nurse/hairdresser) of £24.79 to HDdUHB.

Estimated reach	
Patients receiving specialist hair loss services <i>Including hairdressing, wig services, consultations, information, support, attending any service related to hair loss. Services might be in person or remote (virtual workshop or consultation).</i>	1,520
Patients receiving co-create and support group sessions (online and in-person)	290
Hair loss support packs provided to patients <i>Outreach and face to face including headwear, lashes sent via post and distributed by nurses and allocated support network.</i>	1,380
Patients receiving printed support resources <i>Including sign posting to support networks</i>	3,200
Total patient services/touchpoints	6,390
Nurses and cancer support professionals receiving education and training	115
Number of hairdressers receiving education and training and local hair loss support networks	150
Total professionals educated to support the local network	265

Availability of Cancer Services Charitable Funds

There are sufficient charitable funds available within cancer services to support the cost associated with this initiative:

Fund code	Fund name	Uncommitted balance as at 31.07.2023
T075	Carmarthen Oncology Fund	£84,888.23
T091	PPH Cancer Fund	£43,108.79
T376	Leri Day Hospital (Chemotherapy Unit)	£20,653.96
T440	WGH Chemotherapy Unit	£11,715.76
T584	GGH Chemotherapy Unit	£594,209.51
T705	GGH Oncology	£310,682.02
T720	PPH Oncology	£39,279.71
T865	Ceredigion Cancer Services	£115,179.56
T905	Pembrokeshire Cancer Services	£133,586.65
	Total	£1,353,304.19

To reflect the demographics of cancer patients across Hywel Dda it is proposed that the funding contributions are as follows:

County	Value of contribution	Contribution from
Carmarthenshire	£82,500 (50%)	£82,500 T075 Carmarthen Oncology Fund
Ceredigion	£33,000 (20%)	£20,653.96 T376 Leri Day Hospital (Chemotherapy Day Unit)
		£12,346.04 T865 Ceredigion Cancer Services
Pembrokeshire	£49,500 (30%)	£11,715.76 T440 WGH Chemotherapy Unit
		£37,784.24 T905 Pembrokeshire Cancer Services

The external Withybush Cancer Day Unit Appeal charity that has supported the Pembrokeshire pilot has indicated that it would like to support the next phase of the project. These discussions will be progressed when the outcome of the CFC meeting is known and may result in a lower value of Pembrokeshire charitable funds being accessed.

Procurement and Governance Considerations

The two-year budget of £165,000 for the “Heads Up!” initiative has been developed based on the experience of delivering the Pembrokeshire pilot project.

The main costs associated with the delivery of the service are associated with:

- Training of local hairdressers across the HDdUHB region.
- Community outreach events for local hairdressers across the HDdUHB region.
- Training of local healthcare professionals across the HDdUHB region.
- Patient consultations in person or remote.
- Hair loss support packs for all patients.
- Printed and digital materials and resources for patients.
- Marketing and promotion.

The HDdUHB cancer services team is working with the Hywel Dda Procurement team to ensure that HDdUHB financial processes are followed in relation to this initiative. Although a project partner was identified and engaged with for the delivery of a pilot project, formal procurement advice will be sought to determine the most appropriate procurement route for the delivery of the initiative over an extended period.

Sustainability/Exit Strategy

This initiative is above and beyond what the NHS is funded to provide and due to the current financial climate it is not envisaged that the service could be mainstreamed into NHS exchequer funds following the initial two-year funding period. Cancer services are fortunate to receive significant support from patients, their families and our local communities on an annual basis. The Lead Cancer Nurse and Head of Hywel Dda Health Charities will develop a fundraising strategy for cancer services across HDdUHB to ensure that the service can continue to be charitable funded following the initial funding period.

Argymhelliad / Recommendation

The Charitable Funds Committee is asked to approve £165,000 of cancer services charitable funds to provide a local expert, person centred, holistic hair loss service for patients.

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 £10,000 shall only need approval by the nominated fund manager. All expenditure in excess of £10,000 and up to £50,000 will require the approval of the Charitable Funds Sub-Committee. 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"
Cyfeirnod Cofrestr Risg Datix a Sgôr Cyfredol: Datix Risk Register Reference and Score:	N/A
Parthau Ansawdd: Domains of Quality Quality and Engagement Act (sharepoint.com)	5. Equitable 6. Person-Centred
Parthau Ansawdd: Domains of Quality Quality and Engagement Act (sharepoint.com)	4. Dignified Care 4.2 Patient Information 6. Individual care 6.1 Planning Care to Promote Independence
Amcanion Strategol y BIP: UHB Strategic Objectives:	1. Putting people at the heart of everything we do All Strategic Objectives are applicable
Amcanion Cynllunio Planning Objectives	2E Evidencing impact of charitable funds
Amcanion Llesiant BIP: UHB Well-being Objectives: Hyperlink to HDdUHB Well-being Objectives Annual Report 2021-2022	10. Not Applicable

Gwybodaeth Ychwanegol: Further Information:

Ar sail tystiolaeth: Evidence Base:	Cancer services patient experience survey 2023 Pembrokeshire pilot scheme with Cancer Haircare Patient feedback to clinical teams
Rhestr Termiau: Glossary of Terms:	Included within main body of report

Partion / Pwyllgorau â ymgynhorwyd ymlaen llaw y Pwyllgor Cronfa Elusennol: Parties / Committees consulted prior to Charitable Funds Committee:	Cancer services management team Cancer Haircare charity NHS Wales Shared Services Procurement team
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Effaith: (rhaid cwblhau) Impact: (must be completed)	
Ariannol / Gwerth am Arian: Financial / Service:	No current exchequer funds available to support a project of this nature hence a submission being made to the Charitable Funds Committee.
Ansawdd / Gofal Claf: Quality / Patient Care:	Patient experience will be enhanced as a result of the service and their overall care improved.
Gweithlu: Workforce:	No direct impact on existing workforce. All Chemotherapy Day Unit will identify a 'Hair loss Champion' from within the existing staffing establishment to facilitate the local service.
Risg: Risk:	A risk assessment will be undertaken to ensure that any potential risks are mitigated before the establishment of the project and lessons learnt from the Pembrokeshire pilot.
Cyfreithiol: Legal:	Not applicable
Enw Da: Reputational:	Not applicable - As the service directly benefits patients and NHS staff there is no likelihood of public/patient opposition.
Gyfrinachedd: Privacy:	A Data Protection Impact Assessment (DPIA) will be undertaken in conjunction with the Information Governance Manager before the establishment of the project.
Cydraddoldeb: Equality:	The service will ensure that access is appropriate and equitable for all people, their hair type, ethnicity and how they identify themselves. This will be monitored by the Cancer Services Management team.