Welcome to

**Paediatric Palliative Care in Wales**

September 2016

**Introduction**

Welcome to Wales, and to Paediatric Palliative Medicine. This is a two-year programme leading to accreditation in the paediatric subspecialty of palliative medicine. It is primarily intended for those who will go on to be consultants in paediatric palliative medicine, and by the end of the programme trainees should aim to have attained level IV according to the APPM curriculum.

**How we work**

The population of Wales is three and a half million. The all-Wales tertiary service is coordinated from the Noah’s Ark Children’s Hospital for Wales in Cardiff, and extends across the whole of Wales. There will be times when your work will take you to any of the hospitals in Wales, to the patient's home, to either of the two children's hospices in Wales (especially Tŷ Hafan) or to one of the special schools. There are secondary paediatric palliative care services in each of the Local Health Boards in Wales, but in practice you will spend most of your time working with the teams in Cardiff and Swansea. Although the majority of the Welsh population lives in the South, you will have the opportunity to travel to North Wales from time to time to help with satellite clinics there.

Training in Wales will include a significant component of exposure to the adult specialty, which we consider to be important. This may be in the form of a day a week or in a block, at one of the adult hospices in South Wales.

The core tertiary team provides an all-Wales specialist service in paediatric palliative care and works closely alongside specialist palliative care nurses from each of the seven Health Boards in Wales and at Tŷ Hafan Children's hospice. A paediatrician with a special interest takes the medical lead for palliative care in each region, again working closely with the palliative care nurses and providing a tier of secondary level expertise (APPM level III). There are six paediatric oncology outreach nurses across Wales who provide palliative care nursing expertise to children with cancer. Finally, there is input into the team from social work and chaplaincy services where possible

**Clinical Training**

* Training offers graduated responsibility, with an expectation that at the beginning of training you will discuss all patients with the clinical supervisor, but that as the programme progresses this will give way to increasingly independent clinical working, supported always by good team communications.
* During office hours, your middle-grade responsibilities will be in paediatric palliative medicine:
  + Inpatient Palliative Care based at the children’s hospital for Wales, Cardiff University
  + Medical support, including home visits, for oncology and palliative care community outreach teams caring for children at home
  + Specialist palliative care to Children’s Hospice (Tŷ Hafan) one half day per week
  + Liaison with regional secondary care teams (including clinics and joint visits where necessary)
  + Liaison with primary care teams (including visits where necessary)
  + Outpatient symptom control clinics at various locations across South and West Wales.
  + Special school clinics in Cardiff
  + Secondment to an adult specialist palliative care team
* There is currently no out of hours on call associated with palliative care. You will participate in the middle-grade paediatric rota at the Children’s Hospital in Cardiff, which is shared with other trainees covering general and specialist paediatrics (including palliative care). The full-time on call commitment is currently one in eleven.
* Trainees are strongly encouraged to undertake the Cardiff University Diploma/MSc in Palliative Medicine (paediatric option) during their post. The Diploma offers a robust theoretical underpinning to much of the practical clinical work you will be undertaking. The Diploma is intended to deliver competencies to level III of the APPM Curriculum, but it does not necessarily deliver all of them.

**Research, audit and teaching**

Wales is a leading centre for paediatric palliative care teaching and research, and you will be expected to participate actively. You will be expected to perform audit once or twice each year of their training, on a subject of interest to be agreed with their clinical supervisor. You are encouraged to develop a small research project during your time and will be supported in taking this to presentation at local, regional or national and international conferences. A word of warning – research takes much longer than you think to set in motion. Start thinking about it in the first few weeks of your post.

There is a Paediatric Departmental teaching programme in which as a paediatric trainee you will be allocated sessions. There is also a regular PPC Journal Club, and you will have the opportunity to participate in an active and varied programme of teaching across Wales, particularly to junior paediatric trainees and to nurses. We will encourage you to participate and to be observed while teaching.

**Conferences and study leave**

We will support you wherever possible in attending relevant courses and conferences. These would include, for example, the biennial international conference in paediatric palliative care hosted in Cardiff itself, APPM Study Days and the Rome Conferences. Courses on communications skills are particularly valuable.

Cardiff is the leading centre for academic training in PPM in the UK. We would encourage you to complete the rigorous post-graduate Diploma in Palliative Medicine and to consider the MSc in research methodology in palliative care. We will aim to offer extensive teaching to support this.

**Resources you will need**

* We have put together some resources in a shared DropBox folder *Paediatric Palliative Care Resources* with which we will link you once you have an NHS email address. These include papers, presentations and audio and video resources.
* There is a Google Calendar which includes details of events such as leave that affect the whole Network. The username is [PaedPallCare@gmail.com](mailto:PaedPallCare@gmail.com) and the password is CicelySaunders. *Please note this is NOT secure and should not be used to record patient-identifiable data such as addresses.*
* There are two curriculum documents you should have:
  1. The **RCPCH Curriculum in Paediatric Palliative Medicine** is available from the RCPCH website. It sets out the competencies you must have in order to obtain a CCST, and you should upload it into your RCPCH e-portfolio.
  2. The **APPM Curriculum**, which is in the PPC Resources folder, sets out in more detail what you should aim to cover in the next two years.
* The ‘course textbook’ is the **Oxford Textbook of Palliative Care in Children** 2nd ed. (Goldman A, Hain R, Liben S). Oxford University Press; 2012. ISBN 978-0-19-959510-5.
* The ‘course handbook’ is **Paediatric Palliative Medicine (Oxford Specialist Handbooks in Paediatrics)**  - Hain, R., Jassal, S. Oxford University Press: 2010. ISBN 978-0199236329. *NB A new edition will be coming out in the next few months, which will include the APPM formulary (below).*
* **Symptom control guidelines** are available online without charge on http://paed.pallcare.info/index.php
* The **APPM Formulary** (in the PPC Resource folder, and also available on the APPM website) is a valuable resource for prescribing some of the more unusual medications in PPM.
* A large number of relevant articles are available in the PPM offices, in hard copy and electronic form. They are filed/stored using an Endnote Library entitled *Index,* which is in the PPC Resources folder.
* A range of other textbooks is available in the PPC office. You are welcome to use any of them, but please do not remove them from the office.

**Consultants/supervisors**

Dr Richard Hain

Consultant in Paediatric Palliative Medicine

Noah’s Ark Children’s Hospital for Wales

Heath Park, Cardiff CF14 4XW

029 2074 3373 (sec: Lin Baker)

07976 552329

richard.hain@wales.nhs.uk

Dr Megumi Baba

Consultant in Transitional and Paediatric Palliative Medicine

Tŷ Hafan Children's Hospice

Hayes Road

Sully

CF64 5XX

029 2053 2199 (sec: Rosie Clarke)

07879 815755

Dr Jo Griffiths *(on maternity leave until January 2017)*

Consultant in Paediatric Palliative Medicine and Community Paediatrics

Department of Community Child Health

Central Clinic

21 Orchard Street, Swansea SA1 5AT

01792 516481 (sec: Lisa Webb)

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**Indicative weekly programme (very variable in practice !)**

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|  | RH | MB | JG |
| Mon am | Ward round (PPC offices, NACH)  Clinic (COPD, NACH) | Clinical meeting with care team and CNS (Tŷ Hafan) |  |
| Mon pm | Satellite clinic (Serennu) | Management meeting  Patient admission  (Tŷ Hafan) |  |
| Tues am | 10.00 Tutorial (McD)  Patient visits  (TH) | (Tutorial)  Clinical work  (Tŷ Hafan) |  |
| Tues pm | IPFR Panel meetings | Supporting work |  |
| Weds am | All-Wales MDT/Journal Club (2nd Weds)  (‘The Hub’ NACH) | All-Wales MDT/Journal Club (2nd Weds)  (‘The Hub’ NACH) |  |
| Weds pm | Ward round (PPC offices, NACH) | Ward round (PPC offices, NACH) |  |
| Thurs am | Satellite clinics (various) | TYA MDT meeting. Transition MDT  UHW) |  |
| Thurs pm | Domiciliary visits |  |  |
| Fri am | Supporting work | Transition work  Clinic/Domiciliary |  |
| Fri pm | Supporting work | Hospice clinical work (TH) |  |

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| NACH = Noah’s Ark Children’s Hospital for Wales | TH = Tŷ Hafan |
| McD = Sully branch of McDonalds  Ty Verlon Industrial Estate, CF63 2BE | TYA = Teenagers & Young Adults |

*The full list of team members, complete with contact details, is included below. You are encouraged to do home visits with the palliative care nurses wherever possible (oncology and non-oncology).*

**WELSH PAEDIATRIC PALLIATIVE CARE NETWORK**

**TELEPHONE NUMBERS**

|  |  |  |
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| **SOUTH & WEST WALES** | | |
| **CONSULTANTS:** | **Phone Numbers** | **Post/Health Board** |
| **Tertiary specialists:**  Dr Richard Hain  Lin Baker  Dr Jo Griffiths  **Lisa Webb**  Dr Meg Baba  **Clinical leads:**  Dr Torsten Hildebrandt  **Melissa Boreham**  Dr Bethan Thomas  **Alison West**  Dr Jyotsna Vaswani  **Helen Williams**  Kathryn Lewis | **029 2074 4490**  07976 552329 (Personal)  029 2074 3373  07977 571272 (Personal)  **01792 516481**  07879 815755  **O1656 752715**  **01443 443443 Ext. 4210**  **01633 234556**  **01437 773359/773209** | Consultant in Paediatric Palliative Medicine, Cardiff & Vale UHB + Network Clinical Lead  Secretary to Dr Hain  Consultant Community/Palliative Care Paediatrician ABMU (Swansea)  Secretary to Jo Griffiths  Consultant in Transitional and Paediatric Palliative Medicine  Consultant Paediatrician ABMU (Princess of Wales Bridgend)  Secretary to Dr Hildebrandt  Consultant Paediatrician Cwm Taf  (Royal Glamorgan)  Secretary to Dr Thomas  Consultant Paediatrician, Aneurin Bevan (Royal Gwent)  Secretary to Dr Vaswani  Paediatric Consultant  Withybush  Hywel Dda |
| **SPECIALIST REGISTRAR (Cardiff):** | | |
| Dr Tim Warlow | Tel: TBC  Pager: 07623906243 | Specialist trainee in PPM |
| **CLINICAL NURSE SPECIALISTS:**  **Palliative care (non oncology)** | | |
| Patricia O’Meara  Lynette Thacker  Kathryn Macsorley  Vera Clement  Jayne Thomas | 01633 618023/618020  07957 640530  07773 281621  07970 465787  029 2074 5634 (office)  07798 668051  01685 728568  01239 623378  07887 948909 | Aneurin Bevan  ABMU (Bridgend/Neath Port Talbot/Swansea)  Cardiff & Vale  Cwm Taf LHB  Hywel Dda |
| **Paediatric Oncology Outreach Nurse Specialists** (Based in Children’s Hospital, Cardiff)**:** | | |
| Angela Gallagher  Annie Jenkins  Rowena Jones  Lesley Lewis  Rachel Parry  Jane Cope | 07792 484920  07779 319518  07717 478638  07980 735090  07779 319483  07855 504222 | Covers ABMU  Covers CAVUH, Cwm Taf, AMBU  Covers Hywel Dda & S Powys  Post share AB  Post share AB  CNS for brain tumours |
| **Clinical Specialist Physiotherapist for transitional palliative care:** | | |
| Sarah Clements | 07805564897 | Based at UHW, C&VUHB, covers all Wales |
| **Tŷ Hafan Children’s Hospice: Tel: 029 2053 2200 Fax: 029 2053 2202** | | |
| Carol Killa  Tracey Jones  Beth Morgan  Dr Rhodri Lewis  Linda Bishop  Sara Jones  Shift Leader | 029 20532200  029 20532200  029 2053 2200  07764 574 877  029 20532200  07977 173 921  029 20532200  07917 436 030 | Director Of Care  Head of Community Services and partnerships  Head of Hospice Services  Hospice GP  Paediatric Palliative Care Nurse Specialist  Sara.jones@tyhafan.org  Paediatric Palliative Care Nurse Specialist |

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| **NORTH WALES** | | |
| **CONSULTANTS:**  Dr Valerie Klimach  Dr Madalitso Kubwalo  Dr. Artur Abelian    Lesley Jones  Secretary | 01492 807503  01248 384983  01244 538883    01248 384384 | Betsi Cadwaladr (Conwy)  Betsi Cadwaladr (Bangor)  Betsi Cadwaladr (Wrexham & Flintshire)    Lesley.jones5@wales.nhs.uk |
| **Paediatric Oncology Outreach Nurses:** | | |
| Eleri Roberts  Mary Prince  Rhian Prichard | 01248 384573  07795 952594  07802371413  01978 725769 X 5769  01745 534890 (direct line)  Glan Clwyd Hospital | Betsi Cadwaladr (Bangor)  Betsi Cadwaladr (Wrexham)  Betsi Cadwaladr |
| **Hope House Children’s Hospice (Oswestry):** | | |
| Kath Jones  [Kath@hopehouse.org.uk](mailto:Kath@hopehouse.org.uk)  Dr Santi Eslava | 01691 671999  santi.eslava@nhs.net | Director of Care for Hope House & Ty Gobaith  Hope House,  Nant Lane, Morda, Nr Oswestry, Shropshire, SY10 9BX  Hospice GP |
| **Ty Gobaith (Conwy):** | | |
| Ann Williams  [ann@tygobaith.org.uk](mailto:ann@tygobaith.org.uk)  Dr Alistair Crawford  Alistair.crawford@wales.nhs.uk  Hospice GP | 01492 651900 | Care Manager  Tŷ Gobaith,  Tremorfa Lane, Groesynydd, Conwy, LL32 8SS |