End of Life Care Consultation

14.06.17. GMC Office, Cardiff Bay

Chair:	**Jane Fenton-May**	Vice Chair RCGP Wales
Present:	**Cliff Jones**	GP and EOL Lead for RCGP Wales
	Tony Bayer	Professor Geriatric Medicine, Cardiff University – dementia diagnosis working in outpatients
	Paul Myres	Chair Academy Medical Royal Colleges Wales (AMRCW)
	Martin Rolles	RCRadiology and Vice Chair AMRCW. Head and neck cancer radiotherapy
	Zaid Makzal	Trainee Rep AMRCW- GP trainee
	Rebecca Payne	Chair RCGP and GP with experience of OOH work
	Mark Taubert	Consultant Palliative Care, Velindre NHS Trust
	Veronica Snow	All Wales Palliative Care Coordinator, Velindre
	Sue Hill	RCS and Vice Chair AMRCW. Vascular surgery and acute care
	Sinead O' Mahoney	Consultant Geriatrician, Cardiff University. Mainly acute services
	Eurwen Pettiti	RCGP Policy Advisor
	Ollie John	AMRCW Operational Manager
Apologies:	**Simon Barry**	Senior Lecturer, Respiratory Medicine, Cardiff University
	Ilora Finlay	Consultant Palliative care, Velindre

Introduction

JFM introduced the reason for the meeting outlining that Primary and secondary care clinicians both have skills in caring for those who have terminal and life limiting conditions. JFM identified how few are good at these discussions with patients, often offering hope of cure or improved management when in fact should be looking at ensuring that they have a good end of life which is as comfortable and supported as possible. JFM explained how GPs may refer patients back to secondary care to see if there are any reversible conditions and if there is not - then GPs and the patients need to be made aware of this. Lastly, how this advice needs to come from secondary care clinicians, so that GPs and the patients, families and carers together with community and secondary care palliative care colleagues can agree and plan the most appropriate services.

Those present introduced themselves and outlined challenges around EOL and areas of interest.

Other points considered:

- Often wrong person at wrong time sees patient with out all information
- End of Life discussions can be part of any medical clinician role. IT should be included in training and will improve with experience
- Trainees and trained doctors often lack confidence in what to do/say.
- High Patient turnover may make it difficult to engage in difficult conversations or plans to change direction of care
- Choose Wisely in Wales looking at shared decision making in stage 4 cancer
- Need for good medical professional leadership
- Co morbidity in ageing patient population potentially compounded by dementia
- Patients often feel the specialist knows best and will not listen to suggestions from GP
- COPD care improving with support of respiratory COPD nurse and discussions re EOL and values of interventions
- Need to link to serious illness program, EOL delivery plan and work of organ donation teams
- Reference to working with Dying matters
- Link to Talk CPR project http://talkcpr.wales/ and Byw Nawr - Live Now (Dying Matters in Wales) http://www.dyingmatters.org/wales
- Reason for discussion need to help patients plan for future early and develop a legacy/ memories for those they love/ their family
- Focus on recognizing when to have discussions about advanced care planning and options
- Importance of recognizing when tests and interventions are inappropriate (eg likely to cause more harm than good or not in accordance with what is important to patient/ family)

Discussion on way forward

Consensus from group was to work towards creating a professionally lead campaign to support doctors to recognise final illness in their patients and to be able to have the conversation with confidence. This is everyone's business.

- There needs to be shared decision making and we need to enable the patient to talk about the issues. This can be more difficult when doctor or nurse does not know the patient e.g. out of hours, night nurses.
- There needs to be more public awareness of the issue and this needs to be linked to things like the Talk CPR and Byrw Nawr websites and messages.
- We need something simple to enable doctors to start to recognise final illness in their patients and change the culture so that it is discussed.
- We need to be aware that not all patients want to know this information and that there may pressure for relatives to hide the truth.
- There must be clear transfer of information and some advance care planning.
- There may be some need to up-skill clinicians. This needs to be available for undergraduate, post graduate and qualified doctors with link to core generic competencies.
- A simple logo and electronic communication could work: See it, call it, do it.

Others to invite: **Lynda Dykes** GP and AE Consultant , Bangor
Ruth Alcalado Consultant Physician , Royal Glamorgan Hospital
Dave Jones, RCoA, Cardiff

The AMRCW have agreed to sponsor this work (Confirmed at AMCRW Council 14.06.17)
There need to be links to the Deanery, JFM will follow up