

Workshop Outcomes:

Questions	Communities	Professionals
<p>What are the barriers to access palliative care, real or imagined?</p>	<ul style="list-style-type: none"> • People may believe that it is expensive as they may have to pay in other countries. • Service may not be known about as does not exist in every country. • Domiciliary palliative service doesn't always exist. • Lack of trust in medics and authority. • Preconceived negative ideas about a 'hospice' 	<ul style="list-style-type: none"> • Lack of knowledge • Fear • Perception of having to pay • Professionals not signposting • Language barriers • Not understanding "palliative care" • Cultural influences • Stigma • Denial • Shock/emotional impact • Previous experiences • Depression- after diagnosis • Racism- thinking they would be treated badly • Lack of support from family/friends • Overstretched NHS • Negative staff attitude • Low expectations
<p>How are people in the last year of life being cared for in the communities? Who is providing this?</p>	<ul style="list-style-type: none"> • Family (immediate) • Church- spiritual support • Friends/neighbours • Encouraging and promoting independence • Visiting Reg- helping with travel • Online shopping- keeping home/garden • If you can pay then you could be cared for by an institution but this does not often reach H&S requirements • In villages/small communities, everyone pitches in together. 	<ul style="list-style-type: none"> • Often disjointed and fragmented, with some groups not accessing any care • Power belongs to professionals • Domiciliary care • District nurses • Churches create awareness and may offer support/counselling/communion/rite of passage • Support for carers • Carried out by family and friends • Community nurses/GPs/Private care/counsellors • Hospice/voluntary/ambulance/carers services • Religious leaders • Support groups

<p>How can we explain palliative care in simple terms? What would people understand?</p>	<ul style="list-style-type: none"> • Explain what the support is- “palliative” indicates “dying now”. • It is a taboo subject to discuss so get families in straight away to look around and speak to staff. • Help to support them, give practical information that can ease a person’s life, help them stay positive, active and creative. Help them to achieve things within this period of life to make it better than the last phase! • With families too, help them to “pass” in the best possible way. • Encourage the patient to ask about poor health, don’t use words like ‘dying’ or ‘end of life’ (EOL) • Build bridges and relationships, don’t give them weeks/months breaks. 	<ul style="list-style-type: none"> • Comforting care for an onward journey • Holistic care for family and patient (financial, emotional, spiritual, physical) • Managing symptoms to give a better quality of life for as long as possible • Need to give examples/telling own stories and share experiences • Another word for “palliative”- ‘treatable, not curable’, ‘not going to die immediately’ • A soap opera storyline- raises national awareness • Community conversations- providing a safe environment to talk and share. • Comprehensive care given to an individual which is personalised for them and their families needs so they have a dignified end of life with pain control.
<p>How can we communicate the message of palliative care to the local communities?</p>	<ul style="list-style-type: none"> • Contact with professionals • I.T.- Twitter, Facebook, Forums • Community centres • Advertising from community activists e.g. Polish media websites • Leaflets in GP surgeries • Schools • Better terminology “Supportive Care Team” • Ethnic shop leaflet drop • Improve level of education eg. Roma • Leaflet of different life stages 	<ul style="list-style-type: none"> • Ask communities • Focus groups • Community champions • Identifying stories from those using services and gaining insight from their previous experiences • Community events- running and attending them • Community volunteers- in religious events, going up to people rather than just standing at a stall. • Word of mouth • Death Cafes • Local media/radio • Schools • Hospice open days • Local social events • Work place advertising • Visiting people in the communities and getting feedback

<p>How can services meet the cultural and equality needs of communities best?</p>	<ul style="list-style-type: none"> • More language services (interpreters)- gain greater understanding • Health centres to have language drop in times with native speakers ie. Polish 9-10am, Slovak 10-11am • Build up trust- more face to face interactions • Use more social media- free newspaper being distributed + printed here. • Speciality shops, for example, Grocers • Schools/universities • Get the message out + easier access • Use more language line- ESOL classes. 	<ul style="list-style-type: none"> • Ethnicities, genders, level of qualification, mode of communication and how its translated, culture, faith and understand values- some cultures need family inclusion and some don't. • Involvement is key to understanding- proactive and co-design (different communities to co-design the services) • Take conferences into the community (otherwise you will not create enough awareness)- eg. In Swale, Eastern Europeans are in farms which is disjointed and they may not be able to travel. • Raising awareness of how to navigate health care system, awareness of benefits of the service, screening programmes etc. • Local services knowing their communities eg. Demographics, culture needs etc. Key workers need to link with communities, with the GP being a pivotal role. Need to link with organisations such as schools to target specific groups. • Minority groups need involvement in programmes so they can be reached and get awareness.
<p>In the last year of life what will you find the biggest challenge when caring for a member of your family?</p>	<ul style="list-style-type: none"> • Staying positive and active. • Prioritising other responsibilities eg. Work and family • Family relationships becoming strained- different opinions, many arguments etc. • Money problems if they are off work, benefits • Accessing the appropriate services- where to go? • Maintaining a good relationship with partner, family members • Taking care of themselves and rest of family • Communication • Physical distance • Fulfilling their wishes • Ignorance about the complexity of their condition 	<ul style="list-style-type: none"> • Fear of permanent separation • Worries about the length of process and how they can cope. • Remaining cheerful around the person • What happens if the person is in denial about the condition • Lack of support from primary/secondary healthcare • Lack of knowledge and guidance • Self care (respite, wellbeing, supervision) • Access to information • Financial advice • Counselling

	<ul style="list-style-type: none">• Sometimes there may not be any immediate family members• Getting support from the GPs• Getting the right services and care from day 1• Having someone to talk to outside the family	<ul style="list-style-type: none">• Social isolation, who to talk to? Are you doing the right thing?• Family dynamics• Logistics• Cultural expectations• Meeting/knowing the patients wishes• Lack of normality and privacy (lots of visits, carers, nurses etc)
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