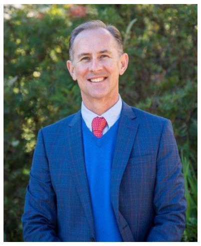
GP LINK Lunches | Xanthe Sansome

Dr Kenneth McCroary, Chair of Sydney South West GP Link, hosts a series of meetings with clinical/ political/regional individuals or organisations to discuss issues and solutions for GPs working in South Western Sydney.


Xanthe Sansome


Ken McCroary

I don't believe it is widely recognised but our region is slowly developing to become the dementia hub of Australia. That is to say during the next 10 years or so, South Western Sydney will have the greatest number of people suffering with dementia per resident than in any other region in the country.

With our advocacy comes forward planning and that includes educating colleagues around items such as advance care directives. As the region ages and develops more chronic and complex health issues I thought it may be a good opportunity to touch base with someone from Advance Care Planning Australia.

I have been lucky enough today to be joined by Xanthe Sansome, the National Program Director at Advance Care Planning Australia.

Xanthe has worked as a physiotherapist in numerous aged care, research and project roles, and as manager of a palliative care collaborative and Queensland's Statewide Office of Advance Care Planning. She has completed her Masters thesis on the end-of-life preferences of people over 85 years and is passionate about ensuring a person's life story and preferences for their end-of-life care are both known and respected. She hopes to expand her program to increase the awareness and uptake of advance care planning across Australia.

GP Link is certainly keen to do our part in increasing awareness and I welcome you Xanthe. Tell us about advanced care planning and directives if you can please.

Xanthe Sansome - Advance care planning is really about planning for our future healthcare. None of us know when we may need someone else to make a decision on our behalf about our health or our future care so it is a good idea to think about and talk about what we may or may not want for our future healthcare and also to write that down in an advance care directive so that in case anybody is making a decision on your behalf and they are a bit upset about the fact you are in hospital they have that in writing as a bit of a safeguard for you. It can really include anything from medical treatment about ventilation and intubation and ICU, CPR right through to surgery, chemotherapy, dialysis and then right down to good pain management, palliative care and what brings us quality of life. Or the presence of family, special music we like being played and whether we would like people to be around us or not. Even the pace we might find comforting especially if we were unable to communicate those preferences at the time.

Ken McCroary - Great thank you. Now what about the organisation? Advance Care Planning isn't it?

Xanthe Sansome -Advance Care Planning Australia yes. We are a national program funded by the Australian Government and we provide a range of services to help people. We have a phone line people can call 1300 208 582 and they can get individual help and support about their advance care planning needs. Health professionals or Individuals can call that number. We also have some training modules online people can look at, and again some for health professionals and some for general public. A range of factsheets and resources as well. We conduct webinars from time to time especially during Advance Care Planning week and we have a whole range of information on our website about advanced care planning in your state or in your specific situation, for people with dementia, people with cancer, people from other cultures. We have languages factsheets on our website as well so if anybody is looking for information they can certainly go to our website or phone the support service for more information.

Ken McCroary - One of my biggest challenges is increasing awareness and hence uptake of advance care planning. How do you recommend that we try and achieve this?

Xanthe Sansome - Good question and something we struggle with too sometimes. But I think most people are afraid to talk about dying and death and that makes sense. None of us really want to think about that and yet most of us acknowledge that one day we will die. If we are dealing with a member of the general public (a health professional dealing with a member of the general public) it might be about just when someone has been admitted to hospital. We ask them how was that? Was there anything about that admission we wouldn't want next time? Perhaps we need to talk about that a bit further. Or if you are a member of the public actually asking your doctors what this treatment might mean for me, where will I be in six weeks, six months, six years, how will that impact my quality of life. So all of those things together help to raise the awareness. We have some conversation starters on our website as well that can get people thinking or be good conversation starters for health professionals to ask individuals. You know what matters to me in my life, in my health and what situations would I find unacceptable which is sometimes easier to answer than what we actually want.

Ken McCroary - Yes, so we are clear on what we don't want aren't we?

Xanthe Sansome - Yes often we find that might be easier to answer. Especially if they have seen a family member or somebody go through some healthcare treatments, and they think 'oh I wouldn't want that'. It can be a good place to start with some people. The other places where we could start is just by putting somebody as the decision maker. So somebody to be your enduring guardian and telling them what it is you would or wouldn't want so at least you have someone as back up and can make decisions on your behalf. If you were suddenly unwell and unable to make those decisions or even if you were sadly involved in an accident and people were making medical decisions on your behalf.

Ken McCroary - And that person can be pretty much anybody can't it? They don't necessarily have to be related and next of kin do they?

Xanthe Sansome - Absolutely they can be anybody that you can choose and trust. They do have to be over 18 years of age and it is important you just tell them everything you would want and also tell those around you your family members who it is you have appointed. It is also a good idea to share with those other people what you have told your enduring guardian so there is no conflict about the decisions being made. It does just take that burden off the immediate family sometimes if you appoint somebody who is capable of advocating for you but perhaps with a little less emotion than your most obvious family members which is often the case, people often chose their spouse or adult children but of course they will be the ones most emotional if you are in a situation that needs decision making on your behalf. We often find in some communities in the LGBTIQ+ community, for instance, that the actual biological family is not their preferred decision maker. So in most communities it is really important that people articulate who they want to be their decision maker because then they are legally appointed as that person.

Ken McCroary - And I think you have mentioned the word trust and it is someone that you trust to do not necessarily what everyone else may or may not believe is the right thing or the thing that they want it is about what the individual is wanting isn't it?

Xanthe Sansome - It is about someone is advocating for your preferences and your wishes and not what they think is best for them which sometimes happens.

Ken McCroary - Yes and I think we as physicians and clinicians can learn from that as well. It is patient defined what they want and what is important and that is the outcome they are seeking.

Xanthe Sansome - Yes and sometimes we don't understand those decisions, but it is important we do respect those decisions because they are the person's right. Their right to autonomy and self determination to choose what treatment preferences they would or wouldn't want that is correct.

Ken McCroary - Yes great point it is not what we believe or what we think or what we understand it is purely the individual's decisions about what is important to them and what they believe and how they are comfortable. You mentioned not making decisions or not having people make decisions in times of emotion. I always found one of the great selling points of advance care planning directives, that these decisions, have already been discussed, they have already been finalised, they have already been like you said written down. So talking about it way before the event is really important isn't it?

Xanthe Sansome - It really, really is. It just helps people kind of get the concept. I tell my kids all the time if I am ever in a serious car accident and I get a significant brain injury that I don't want to be kept alive on a ventilator. Although they go "oh come on Mum", the idea is they are getting used to that concept so if it were to happen they are not going to be troubled by anybody making that decision for me. So talking about it as often as possible is really helpful and like I said it prepares people for those times when it comes up, and ideally if clinicians can sort of re visit on an annual or semi-annual basis to just kind of check in to make sure that those preferences and wishes are still the same, that family have been included in those conversations. Again, it just kind of keeps everybody on the same page and provides an opportunity for people to say remember mum said that last time and then someone will go that is right she was pretty clear about that. It just takes all of the sting out of making the decision and it allows people to focus on just providing quality care and love and support for the person rather than having to make a very, very difficult decision in an emotional state.

Ken McCroary - The other challenging concept I find is the family and how the individual may have different thoughts, wishes, beliefs to family members and even amongst the family members people have their own autonomic views. So again it just means we don't have to be worrying and fighting and being challenged by it at the end it is all dusted and at the end we can just be embracing our loved one and beginning grieving processes and not having these other traumas to deal with don't we?

Xanthe Sansome - Absolutely, I think people think they are just going to fall asleep and die naturally and there is not going to be any decisions that are required but it is amazing how many patients require some decisions and whether that is which hospital or pain relief or the next operation or the next treatment modality. If they have talked about it, it just makes it so much easier for the family and then the family unite, and it is not a tension point that stays with them long beyond the death of a person. I heard a great phrase Ken about talking about pregnancy doesn't get someone pregnant and similarly talking about death doesn't bring death on and that has stayed with me a little bit because that is true. By raising the topic of death and dying is not actually going to kill a person and so now we have it as a bit of an in joke and can be a kind of handy thing for clinicians to use sometimes.

Ken McCroary - Yes despite the neurosis and anxieties out there that no we can't talk about it, it might make it happen it is not logic. So that was my next point actually the inevitability of death and then as a society, the community, I just really don't think we do death well do we?

Xanthe Sansome - No, I think we all know that death is going to happen, but I don't know that we think dying is going to happen and we all put it off because it is not something that we want to think about. Yet we do wills and sometimes we do funeral plans and those sorts of things considering about what is going to happen after we die but we are not thinking about ourselves and that healthcare that we are going to receive prior to it.

Ken McCroary - Well said, it should be the first thing that we are talking about. The funeral plans and the distribution of estates that's to be done after we have planned our dying isn't it.

Xanthe Sansome - That is right, and we are organised with most things because we don't want to cause distress to the family, but we don't seem to realise that actually there is a certain level of distress and conflict within the family prior to dying at times if these conversations or documents are not completed before they are needed.

Ken McCroary - Now an issue too with this space is that even the clinicians themselves are not always comfortable and confident in talking about death and dying and talking about planning such a thing as a directive or an official plan. So what clues do you have for my colleagues about how to bring up the discussion if it is something that they are challenged by?

Xanthe Sansome - As I said we have got conversation starters on our website that just might help. Like, so what was it about that event that troubled you? It might have been a hospital admission or something. Or what brings you quality of life? What is really important for us to know about you while we are providing care for you because we want to provide optimal care that is tailored to you and your situation. So what is it we need to know about you and about your preferences that would make us provide the best care for you? And sometimes opening it up in those kinds of ways really helps. People start to talk about things, and you can delve a little deeper. What is it about that that you wouldn't want again? Or why was it that that bothered you so much or what was it that evokes tears even as you say that. What is it about that phrasing that just makes you so upset? So I think using the existing situations. When a partner dies sometimes that is a good opportunity to raise it with the spouse. Obviously sensitively but just to say can you tell me about the death of your partner? How was that and get them to sort of talk through that and even just say is that something that you would want for yourself? Or is that something that you wouldn't want for yourself? So there is often lovely little triggers that aren't just your normal conversation. Appreciating time is of the essence and so supporting people even just a call at our support service so that skilled staff can help you talk through that conversation if that is needed.

Ken McCroary - My next question was really how we learn more about the advance care planning and I think you covered a bit about that already with your website and the items that you have available for us. How else can we learn about advance care planning and directives?

Xanthe Sansome - The NSW Government also has websites. There is a range of videos on the YouTube channels as well that break down advanced care planning into a very simple format and make it really relevant and applicable to people and talk to them about things such as a decision maker and about planning for your future care. So it just brings it down to a really simple format that makes people understand the importance of it. They are in a sort of animated form so they help to break down any stigmas or associations with particular groups and can be used by anybody. But really there is a lot of information on the website. We can post out fact sheets to you as well if people are interested in receiving something in the mail. And people can attend education as I mentioned.

Ken McCroary - We all know the saying who should you do them with and if it is someone who you think you wouldn't be surprised if they die in the next 12 months then that is someone that you should raise the topic within our day to day practices. But it is really not just for elderly people or those that have significant chronic health issues either is it? It is really for people of any age to be getting this discussion isn't it?

Xanthe Sansome - It is absolutely I am sure you know Ken, people that have unfortunately had a son who might have had an accident or a stroke that wasn't necessarily expected and so the decision making can be needed even as young as 18 and even younger in some cases. So it is really something for all of us to be involved in doing ourselves and most clinicians as well just because life happens. Sometimes workplace accidents, car accidents, a heart attack or a stroke so it is something that is really relevant for anybody, certainly anybody that has been diagnosed with a life-threatening illness, complex comorbidities, anybody with early dementia they are certainly people to target for advanced care planning conversations because their healthcare needs are obviously going to be increasing over coming months or years. So it is good to get them thinking about that as early as possible, but I agree with you it is relevant to anybody who clinicians are seeing.

Ken McCroary - Life is fragile. The last thing that the families really deserve is to be traumatised by making decisions that they are uncertain of isn't it? So if we all had these sorts of plans already in place at least that is one comfort you can give to the survivors isn't it?

Xanthe Sansome - That is right because you know that you have actually respected their final wishes in a sense and then acted those. As sad as loss always is you can take some comfort in knowing that you knew and were able to respect their final wishes. It does reduce the anxiety and the stress for our health professionals knowing that they are making the decision that the person would have wanted rather than making the decision in the dark.

Ken McCroary - Yes I try and teach my students and registrars about general practice as a whole of life caring practice and that doing a good death is just as important as doing good healthy life treatments as well. I always include the planning as a part of a good death not just for living symptoms and comfort measures but having things planned is part of our service. As well as having the privilege of looking after people we should also be looking at doing the best we can for them and that would be to discuss things like directives and planning.

Xanthe Sansome - Yes absolutely as a very wise doctor once said to me a one-hour conversation that could save two weeks in ICU. You think if it is that sort of challenge, if it is that comparison I would rather have the hour long difficult conversation and be explaining to family members all that is required in ICU and all of the decisions that might be needed when someone has to choose to take someone off life support. So absolutely, it is part of good living right up to your very last day and that is sometimes a very easy way to put it. How can we care for our patients the best when they are in hospital by choosing their medical treatments and then their life care and in support of their family. One way to do that is by knowing exactly what it is that they want and being able to enact that. So I think you know you sound like you are training your students and registrars very well Ken.

Ken McCroary – Thank you, but yes it part of it if you are passionate about people and their life story then their end of life care is still part of their story and their journey so it is something that we should be talking about more often.

Xanthe Sansome - Absolutely that is a really profound time in a person's life and anyone who has lost anybody will know the days around that death and the dying time and they will remember that quite importantly like they do a birth of a child and so the experiences around that time and the preparation for dying and death absolutely makes the world of difference to people. It is something that we should be talking about much more often.

Ken McCroary - You mentioned a point about talking about post discharge with our patients and I thought that is a really good segue into how or what other times we can bring it up. Here in our practice we tend to bring it up during our chronic health updates with over 75 health checks and all of those sorts of things and that way we can involve our whole primary care team. Particularly our nurses who I believe are excellent in this phase, talking to people and talking with people not just at people like we do sometimes unfortunately. I think you mentioned 'time'. With our system we are not encouraged to spend time with our patients at all. We are disincentivised to do that and that is another problem with our system, but you are right a bit of time saves a lot of effort and a lot of time moving forward. I am just thinking of ways we can improve access to people to spend more time with their doctors and nurses and primary care teams to discuss this topic. It could really make a difference.

Xanthe Sansome - Yes and I think too it is not often one conversation. It is a multitude of conversations. So introducing advance care planning, perhaps with a brochure or with the forms initially as a conversation starter and just saying you know when you come back next time I would like to talk a little bit more about this. I would just like you to have a think about this or have a read through some of this before we talk next time. I agree with you, practice nurses are a great resource who delve a bit deeper and explore the conversation a little bit more and even possibly support someone completing an advance care document. You know just exploring values and preferences and then you know the time of the GP can be used just looking over that and confirming their choices and then signing it off, so there is that safeguard of peoples decision making capacity and understanding of their preferences. So I think you are right it is a whole of system approach. Using practice staff and using any community ACP facilitators that are around. Again if people are stuck they can call our support service line and get people to help. You know just navigate the form and navigate the conversation so they can complete it perhaps 90 per cent and then come to the GP with the remainder.

Ken McCroary - And it is not necessarily required to be a morbid time or a dark conversation. It can be in my experience quite enjoyable. It can be fun to a degree sometimes particularly when you have got this great couple that have been together 50 years and have completely opposite thoughts and plans and diametrically opposed needs for themselves and obviously respect their partners wishes as well. So it can be quite fun and the family really appreciate it when we involve the kids and the grandkids with a copy of their plans. It can be a fun ride to go on with people, as I said not necessarily being morbid and sad. I again encourage people to be having this discussion.

Xanthe Sansome - And people who have had the conversation often say oh I feel relieved to have done that you know. They hadn't sort of realised that it was weighing on their mind and so actually opening the door for the conversation actually provided a great deal of relief for people, especially if they are chronically ill and they have contemplated their death, but they just don't want to speak about it in case it happens. If someone helps just open the door that little bit there is often great relief when they have been able to do it. Yes we have many a laugh in conversations with people when they have said oh gosh don't touch my feet I will kick you in the face kind of comment or give me as long as I have got my taste and my Bundaberg rum every day I am happy. So all of these things can be incorporated into someone's care plan just by having the conversation.

Ken McCroary - Often there is relief and often it is thanks and appreciation for being the one to bring it up. Having that sometimes difficult and challenging but really grateful discussion to plan these things. As I said earlier on some of my colleagues have a problem with brining this up and the individual sometimes really struggles dramatically with bringing it up with their family and friends

and having us be that facilitator, that conduit between patients thoughts and wishes and written plans often can be a great thing for the rest of the family as well.

Xanthe Sansome - Yes absolutely and GPs often know the clients best of all. You know they are their health professional that has seen them through their trials and challenges and can really empathise with them. Just relate with them and encourage them in this process. It really does provide great relief and certainty and comfort, and you know, having had that conversation and supporting somebody to complete their documentation.

Ken McCroary - Yes exactly. Now obviously it can be a bit difficult and there is an inevitability that those that you do those with they will die as well and so as professionals there is that challenge that we have to deal with. These people that you are looking after are going to die and dealing with that all day every day can sometimes get you down. I guess so what I am getting at is you do this all day every day what keeps you keen and so upbeat about what you are talking about here today?

Xanthe Sansome - I think knowing that you have actually enabled somebody to die the way they wanted to die and their family has been supported in that process. To me that is truly valuing an individual and their uniqueness and individuality. You have captured for them or with them what it is that matters most to them, what care they want and then you have been able to support the delivery of that care. In my mind that is one of the greatest gifts you can give to somebody that perhaps you have been seeing for years to be able to see them out of this life almost and delivered care according to their preferences. I just value human beings intrinsically and recognise each person's uniqueness and individuality and I think their care planning is a fantastic opportunity to capture that and to enable that. So it is a real privilege I think to be able to have those conversations and you know when you get better at it you know that you have really met somebody with their concerns and their needs and you have been able to consolidate them into something that is going to be beneficial to them and to their family down the track. So it is really rewarding and satisfying when you have these conversations and people are just go grateful and relieved they have been able to have them and especially with somebody that they can trust.

Ken McCroary - Yes helping people is a plus isn't it?

Xanthe Sansome - Yes it really is.

Ken McCroary - Something comes up as NSW goes through formal legislation is voluntary assisted dying. How is that going to impact with the advance care planning and directives do you reckon?

Xanthe Sansome - Yes Ken we get asked this a lot. So at the moment it is a very clear distinction. When it comes in in NSW you will need decision making capacity to be able to consent to voluntary assisted dying and then to administer the medication so you will need decision making capacity at that point and you can still do advance care planning at that point. However an advance care directive isn't enacted until someone has impaired decision making capacity. So you need decision making capacity to enact assisted dying, an advance care directive only gets enacted when someone has lost decision making capacity. At the moment, you cannot pre-consent to any sort of assisted dying in your advance care directive in any state and that is being looked at. At the moment as Victoria reviews their voluntary assisted dying laws and particularly in the case of dementia. But at the moment they are quite mutually exclusive and there is no crossover or ability to pre-consent to assisted dying in your advanced care planning documents. Nor can you ask somebody else to enact voluntary assisted dying. You can't choose the decision making that they are to assist you with dying that is not legal in any state or territory in Australia.

Ken McCroary - I think you explained that really well. That there is quite clearly a difference between having capacity to chose to leave and losing that capacity to let everybody know what you want and there is quite a difference isn't there?

Xanthe Sansome - Yes absolutely it is really clear. And we encourage everybody to do an advance care plan because not everybody is eligible for voluntary assisted dying. Even if many people chose voluntary assisted dying but many of them don't administer the medicine so either way it is good to have thought about what your future healthcare would be if you did lose decision making capacity or you approach your end of life through morbid disease processes.

Ken McCroary - Absolutely one of the things my organisation is usually quite interested in is wellbeing. Not just for our patients but for our colleagues as well I was just wondering before we wrap up would you have any advice to those in the primary care space to improve their own wellbeing?

Xanthe Sansome - I certainly think there is a view in professional supervision and debriefing opportunities and some clinical reflection on perhaps after each death of a patient so that you can look at ways where you did well and ways that next time that you may be able to improve something. I do think the need for some professional supervision at times to debrief because it can become fatiguing to be providing care all the time and as you say when you lose patients that you have known for some time it can be a sense of moral distress around that so it is certainly something that I would encourage. A way of looking at how your current practice is and ways you can improve it. Also just acknowledging that death and dying does impact all of those if you have known the person. I have heard of places that have actually done some tributes to patients who have died in the practice perhaps just acknowledge the people who have died as a way of providing some closure for clinicians about their patients who have died in that period of time. In residential facilities as well where you know GPs have provided care and there is a way of recognising and acknowledging the life of the person who has passed and even your involvement of care in that person's life and death.

Ken McCroary - Yes that was quite sage, I appreciate that. I will just repeat again that there is a phone number that people can ring Advance Care Planning Australia which was 1300 208 582 that is correct wasn't it?

Xanthe Sansome - Yes that was correct.

Ken McCroary - Excellent alright well on that note I really appreciate you joining us today Xanthe and I really wish you well with the ongoing efforts in this space and all the best with Advance Care Planning Australia and thank you so much.

Remember if you're not a member of GP Link already or you would like to learn more log onto our website at https://sswgp.link/.