

Webinar – The Transition Process

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Speakers: Dr. Jane Ho and Fabienne Edema-Hildebrand

MONA: Thanks everyone for coming along especially to our two speakers today. First, Jane, who is a staff specialist presenting the work she does with TRAPEZE on whole person integrated care and specialist adolescence chronic care services at the Sydney Children's Hospital Network. Then we'll move to Fabienne; she does a lot of work with the transitioning patients and will give us tips on how to stay connected for people as they transition to adult services. Jane can I ask you to get us going please.

SPEAKER (Jane Ho): Thank you very much, hello everyone. I just wanted to let you know I represent TRAPEZE, that's a service within the Sydney Children's Hospitals Network, and so today I'm talking about the transition of young people with Neurofibromatosis. Before I get to talking too much, I wanted to acknowledge the people of the Eora nation who are the traditional custodians of the land on which we meet, paying my respects to elders past and present and those who join the webinar today. The service I work in, TRAPEZE, are the adolescent chronic care service for the Sydney Children's Hospitals Network. We support young people who have chronic conditions between 14 and 25 years old. The core work we do is supporting transition. That means different things to different people, but it doesn't only just mean the transfer from the individual's last appointment as a child and first appointment as an adult. Our values at TRAPEZE: we uphold these principles of advocacy, empowerment, respect, diversity, openness and collaboration and believe young people have the right to be heard and make genuinely informed choices and have timely access to medical services. When it comes to transition, these are the areas that I think about and that I think would be a good idea to cover for very young people who are coming up through the system, and so the first thing is I think about is developmentally appropriate individuation. That means that transition occurs at a time of adolescence, the other major stage in life apart from the first 100 days of our life as babies, there's huge change, huge growth, huge brain development in that period of time.

Again, during this time of adolescence there's huge change. It's such a promising time of life and it's the time when there's a potential for a triple dividend of change, so that the things that we encourage our young people with now, might have benefits for them immediately. In the short term there might be benefits. In the long-term, the patterns of health care and how we teach young people to look after themselves by advocating for their own health, particularly with chronic conditions. Think about these people who go on in the future and perhaps have families of their own and if they are strengthened in knowing how to access health care and knowing how to look after themselves, the benefits will pass to the next generation. It's a great time of change and well worth giving young people the attention and support that they deserve.

Back to developmentally appropriate individuation, because it is a time of adolescence and change, they're becoming

more independent. What we like to try to encourage is the young people to take on more and more of their health care as they are able. For some people they can't perhaps because there may be intellectual disability or some other reason, mental health problems, whatever else goes on - but to the extent that that young person is able, we talk to their parents or caregivers about changing the balance, about how much the parent or caregiver is doing for them and slowly supporting that young person to know what to do, perhaps one day they'll live by themselves, or go on holiday, go out on the weekend, that's those very well on to self-management, again the day-to-day things, if they're taking medication every day, do they know what medicines they are taking? Are they taking it themselves? Do they know how to get a prescription, who do they contact?

Really practical things can be important. Then transfer to adult health care, also really important, because TRAPEZE are located on the children's side. Some are in preparation while children are young, 14, 15, what else needs to be done while they're still in the children's hospital system. Are there any operations that are waiting for them to finish their growth spurt, such as scoliosis surgery - that really would be so much easier to have done while they're still on the paediatric side? Are there other things to be put in place before they leave? I think a GP are the corner stones of health care in our country and other communities supports and of course that psychosocial context for young people, tumultuous time of change in their environment. They might be leaving school, going on to different things. Legally they become an adult, there's voting, the influence of friends and peers is of increasing importance compared to family, a lot of risk taking that settles down but all of these things can have an impact on the health of somebody who has a chronic condition.

So our service - this is a big area but we try to assess all of those areas when we meet with young people - and from that information that we get from assessment we work out a list of tasks and things that need to be done so we can facilitate and monitor what's going on. We co-ordinate and communicate with all the other health professionals who are involved. What is a gastro team doing? What's neurology doing? What's surgery doing? In terms of planning where that young person will go to eventually for adult services. Is it going to be convenient to where they live or somewhere far away? Sometimes talking about those practical things and making sure we can plan everything to be in the one place as much as possible is what we're about. Also back to the GP, strengthen their links with things outside the children's hospital a few years before leaving so that it's not such a big change and that they have other health care providers who will continue with that care.

These are some of the questions that I think of and that would be probably useful for everybody to have an idea about and when thinking about transition planning. What are the needs of that young person? So really focusing on that young person and their world and hearing from them about from their perspective. What are their needs? Of course it goes on to the needs and issues from that parent or caregiver and then also from the teams who are involved because they may be the same or they sometimes may be different. Does that young person have a GP? What are the clinical services

available in their local health district?

There's some structural changes that come when becoming an adult in the health system and one of those important things is that the children's hospitals can take from all over the state, there are no geographical boundaries but that's not so much the case in the adult system where most of the adult care tends to stay within their local health district unless there's a good reason for it not to. In the case of people who have Neurofibromatosis in fact that is the case, not every local health district has a Neurofibromatosis clinic. Do young people need special arrangements, what are their wishes, what are the restrictions, can technology help and does this individual need more advocacy. Now we're lucky because in New South Wales - I'm aware there may be other people from outside our state - but in New South Wales we're very lucky we have two services to support transition, there's my team, and on the adult side mainly there's the agency for clinical innovation transition care network. So in most areas of New South Wales they're mainly located in the adult side, three transition care co-ordinators. However the one in Hunter New England health district, she works in adult and paediatric area, there's a lot of communication and they are the ones who know exactly where the services are for what problems.

So I thought I'd cover some easy tips for preparing for transition. First is start the conversation early. Again, back to this time of adolescence and this growing independence for young people, it's really good to encourage young people to gradually develop independence and the way of thinking and start to encourage them to do things on their own, of course with the safety net of the family in case something doesn't work out. For parents, it's probably a bit hard to take a step back, so it's good there's time to think about it and slowly change that balance. The GP is so important, the GP is the corner stone of primary health services and they have an increasingly important role in unlocking funding in the community, in fact they're the ones you need a referral from in order to access Medicare funding for specialist consultation. They can also unlock Medicare funding for a mental health plan. If a person is feeling anxious or having a period where they're experiencing low mood and want to receive counselling and support for that. Not only are they supposed to be the clinical main person for all of us in the community, but they can also open up access to other services. The great thing about GP's is that they're all ages, another thing is they should be much closer to home than the children's hospital for most people meaning that frequent communication and relationship over a long period of time is important when you have a chronic condition. This way, your GP knows what you're like when you're well and your GP knows what you're like when you're sick and they can act on that and get more help.

The third tip is to get organised. There's a lot of paperwork involved with the hospital but also a lot of paperwork involved with good wellbeing. Some of that could include a Medicare card - once young people turn 15 they can get their own Medicare card. This can be a good idea if you have a chronic complex condition, but also a good idea in terms of independence. For the purposes of the family safety net you can remain linked as a family of course. The other thing is if young people have their own Medicare card and they need to talk to a GP about confidential things for their health

they can do that with some privacy. Another thing is about Centrelink, so some of you are maybe familiar with Centrelink, under 16 years old is the age where the payments change in Centrelink. Families who may have accessed carer payment for that young person under 16, when they turn 16 that payment model changes and if that young person is eligible then that young person them self can receive a pension payment from Centrelink called the disability support pension, or there could be other payments that they might be entitled to, like if they're in full-time study and living away from home could be youth allowance. The carer allowance can continue over 16, but more paperwork is involved. I don't think you can escape paperwork.

So getting organised, thinking about orthotics, procedures, operations, things to do in the children's hospital before it gets too late. If you're looking for more help, visit the TRAPEZE website if you're interested. There's information on there including information sheets, check lists, but there's check lists for young people, families, carers etc. So tip four, know your condition. Young people with Neurofibromatosis it's something that's been lifelong. It's easy for young people when they're a child to have that care with the parent. As they get older because they're more independent it's important for them to be able to describe their condition in case anything happens. Something about I have Neurofibromatosis, this is how it affects me, these are the treatments I'm on, these are the people who look after me and who can tell you more about the condition. Something like that would be very useful for them. identify paediatric needs, I think we've talked about that, transition readiness check list, it's useful, two pages, doesn't take long to complete, you can just tick it, identifies generally, things to work on, a lot of it is self-management and independence. So it's not a test and it's not something that people have to score 100 percent in, it's like golf. You just judge it against yourself and it might be that you might find some points that you could work on from it. So then as we get older we move to talking about transition and planning, wrapping up in the paediatric side and thinking forward to what are the links that need to be made in the adult world, good to have that set out, sometimes it's a simple plan, thinking about goals, short term goals that can be achieved, this idea of listing out the teams involved in your care, their names and that sets it up clearly. That question of do I need the equivalent teams on the adult side and sometimes you need them, sometimes you don't, sometimes that management certainly if things are stable can go back to the GP.

Getting to know the adult world, thinking about what area you live in, where are the services, how easy is it to get to those clinics. So is that hospital or out-patient clinic on the train line, because if there are, for example, two options, and one option is you don't have a car and one option is available by public transport but the other option is not, then it's clear thinking about the logistics and the planning which clinic you'd prefer to go to. Sometimes it's about if you haven't been there for the first time, there might be some understandable anxiety, where do you park? How much does it cost? Where is it in the hospital? And hospitals can be enormous places and you don't know where the out-patient clinic is. Sometimes going in for a meet and greet before the substantial health care transfer happens can be a good idea so that you can make that first real clinical adult consultation more relaxed.

Build a support network, all of us we all need support, different layers, family, friends, professionals, supports, this is a good thing to have in general but also for young people extremely important and sometimes those supports could be from friends who they know through school and friends who don't have the same chronic conditions. Sometimes there are support groups such as the one that we're with this afternoon, where it's possible to meet other young people with chronic conditions or other young people with Neurofibromatosis. For example, in the children's hospital now there's a CHIPS program called Chronic Illness Peer Support, any young person with a chronic condition is welcome to be part of the program and they can use their voice. If something is not right speak up about it and it may not be, maybe positive or negative but sometimes with health care that hospitals deliver, people are unaware of your perspective or what it's like to be on that patient side. If something is not working for you really talk to the health care providers about it because I'm sure that they will be open.

Thank you very much.

MONA: Thank you Jane that was fantastic. Really great to have those tips marked out like that for anyone, it's important for anyone even people without a chronic condition to consider these things. Fabienne, who is the neuro-genetics clinical nurse in transition care will be focusing a bit more on NF.

FABIENNE: Thank you Mona and Jane. I'm going to look at transition care and making the process to adult health care as smooth as possible and some of my learning objectives. Some will recap what Jane shared with us, thank you Jane for that presentation, I'm going to look at the understanding of transition care, GP, the youth assessments that we do in our clinics, what to expect when you come to the adult clinic, I'll touch on the NDIS and my health record, I'll look what should be reviewed for NF patients and a couple of web based tools that can be used to help with transition.

So as Jane mentioned, transition care is a purposeful planned move out of adolescence in to becoming young adults and so in relation to transition it starts for us at about 14 and moves through to 24 years of age. Definition of adolescence, under the World Health Organisation defines an adolescent as any person between the age of 10, to 19 but we stretch it, 14 to 25 years in relation to transition care.

What I really want to stress is when you're in the children's hospital to touch base with TRAPEZE. They're a fantastic service and they really do make transitions smooth. Like has been shown to you by Jane the transition readiness checklist and the individualised care plan, it's great if you can bring those tools along with you to your first appointments in the adult health care setting. It gives us a great idea what of you want to achieve, what we can explain from our side, Jane's tip to come and do a dry run of the hospital and to have a look around is a really great tip because it can be confronting when you first come across and that transition information is wonderful. It really enables us to fill some of the adult side out for you and checking if your teams have nurses involved in their clinics is a good asset to have.

So your GP, I can't stress how important a good GP is. Really important for NF patients because not all NF patients need to be seen by a speciality clinic. There will be some that do but others will be easily managed before their GP, you're on the wheel and the GP is in the middle, on the spokes you have NF clinic team if you're in the northern Sydney local health catchment and you have severe disease you might be coming to see us in the NF clinic. You may see a neurologist or neurosurgeon and they send that information in to your GP and then that information is held and managed by yourself and the GP. I can't stress how important a good GP is, one you can trust and one you can speak to. How do you find a good one? Word of mouth if you speak to friends and family in your local area about the GP that they're seeing to get some good recommendations is a good place to start. Sometimes for adolescents some of them want to stay with the GP they've seen as a child with their family. Others want to break away and get their own GP, sometimes the GP with their family has got a bit older and they'd like a younger one and I encourage to consider patients what they would like. It's fine to stay with the same but it's okay to seek out your own GP if that's what you'd like, somebody you feel comfortable speaking to because you might speak to them without your family.

It's okay to make contact when you're not unwell just to say hi, I'm looking for a new GP. I'd like to consider you to care for me. This is a little bit about my diagnosis, and once you decide on your GP put the information in to your phone so you've got it handy, this is a person that you'll probably call first up when you are unwell and need to be reviewed first.

So the other thing, is that they can refer you, as Jane said, to your speciality services, a GP referral will last 12 months, and a specialist referral lasts three months. Most of the time your speciality services will need a new referral each 12 months so it's a good way to at least be seeing your GP annually and then if you're seeing any specialists you can see them and get your GP to do the referral. Often the GP is more available than speciality services and they offer a broader range of health care issues.

Not everything that you experience will be related to NF and I find often a problem in some of the other clinics I work in is that everyone goes, develop any symptom and straight away they think it's caused by the disease they have which is not always the case. It's good to touch base with your GP to have a quick screen done at the start, as Jane mentioned not only physical but mental health and the GP health care plans that can be put in place. I've spoken to you about seeing your doctor, GP when you're not unwell to meet and greet and ask them, do you treat anybody else with NF? Are you happy to do this health walk with me? I've got NF, I will have certain things I need checked over the years and are you happy to do that with me? Try and avoid these fast in/out GP services. I know that it can be difficult particularly if the cost can be quite high to see some GPs. Some people go to the in and out service because they bulk bill, I know in rural areas of Australia getting in to see the GP can be difficult at times. If I can encourage people to think about making an appointment, if you know you might need a review in six months, try and book it in when you're there; some facilities have that capability. The other thing about already having a GP, someone who is caring for you, is that you don't have to

repeat your story again and again. So remember that if you want a longer appointment to ask for it. If you only want a 15 minute appointment that's okay, be polite and friendly to the receptionist because they're the gatekeeper, if you need to cancel, call them up you want to be friendly terms with your GP practice. As Jane mentioned from 15 years of age you can get your own Medicare card and we encourage that for transition patients. I know in neuro genetics when I do the transition clinic I don't nag our young patients but I encourage them to try and get the cards so that they can. Also if they need to, as Jane said, talk about something sensitive that they can go and see their GP on their own. First thing I stress is we're confidential, the things discussed with us by young people can't be shared unless there's a risk of self-harm.

We have these posters, one about your Medicare card and keep zipped in our clinic spaces. They cover the years 2017 to 2024 and these I find really interesting as the concerns for young people, top issues and you can see coping with stress was the top one, school, study problems, going down the line, alcohol, gambling and from these information gathered for the framework and prior to that we carry out what's called a HEEADSSS assessment and this is an assessment that practitioners or nurses, doctors in the adult setting use to assess how young people are going and there's no wrong answers. No need to be nervous, we're just getting to know you, and help you as best we can.

We work through the framework in the HEEADSSS assessment where we discuss your home environment, who lives with you at home, we ask whether you're comfortable there and it's safe, we then go on and discuss, further, generally like a conversation that we have about employment, education, eating and exercise, diet, might discuss computer use which I find is a really big one that lots of people with chronic illnesses use a lot of computer gaming and Facebook and other platforms, a real social connection for them. Then we look at what activities, hobbies, peer relationships and we'll discuss drugs, cigarettes and alcohol also illicit drug use, sexual activity, sexual health and give advice, we also do scales to check for depression and mood problems, we ask about sleeping patterns, we look at your safety. It's a good way for me as a nurse to be able to identify if there's any concerns. Then talk to the young person about getting a little bit of information if there are any problems and looking to see how we can address those.

What to expect when you get to the adult hospital, I want to start by saying we're not as colourful as the children's hospital. I was amazed when in Melbourne Children's Hospital there's a meerkat enclosure, we don't have anything like that which is a shame. It would be nice.

Sometimes you can wait long periods when you're waiting for adult services and I encourage people to bring with them something to read and something to drink, mobile phone and play a game, can be boring having the wait time and we're doing our best to prevent those, we see a large numbers of patients. At the children's hospital often you have a multidisciplinary team but in the adult setting there's not a lot of those, it might be that you come to your clinic appointment and only see one doctor if you're lucky a nurse or allied health professional that works with them but that's

it and you won't get a long consultation probably 15, 20 minutes. In the clinic I work with we're a bit more generous and you get an hour but it's not a lot of time.

Our doctors will begin to ask you about your health. At the start when you first come to transition we will speak to your parents or caregiver or significant other with us. As time goes on that will change and we'll direct our questions to you about your health so try and be assertive if you can, you'll get to know us. We hope over the time you transition you'll become more comfortable with us and talk about your care needs openly. Once you're at a stage where you're no longer bringing your parents and there are times we might start the appointment with you and your parent then ask your parent to leave and go to the waiting room, when the period is finished you are welcome to bring a support person with you, partner, friend or still your parents if you want to have them there that's not a problem and start thinking about, as Jane mentioned, about getting organised. I really encourage people to get a health folder where they can have copies of results, MRI scans, eye examinations when they go to appointments they've got some of their recent results.

The other thing I wanted to mention with private health insurance, whilst you're transitioning, you're probably under your parent's private health if they have it. Once you're a student and in your 20s and you've finished university you may find there's a stage where you're no longer covered by your parent's private health insurance. When you need to consider, do I want to get it for myself and have an examination of the many different companies that offer it and it's about finding the one that's right for you.

So the NDIS is the national disability insurance scheme. A lot of patients that come from the children's hospital already have this put in place, however at times your needs change when you're in the adult world and you can apply for the national disability insurance scheme online. If you're aged between seven and 65, if you have Australian residency, if you need support from a person because of a permanent or significant disability, if you have special equipment you need to use, if some of your support now would reduce your future needs, if you answer those questions yes you can apply. We do support patients in either maintaining their annual reviews for the NDIS or applying for the NDIS. So it's something that's part of our clinic and will help you. Your GP is another person that helps and if you don't already have it in place then you need to register online first and get the speciality, specialist groups that assist with your health care to write letters in support of you having access to that. An occupational therapist can be helpful but I think look at the start, at the website first.

My health record, so My Health Record what does that mean for you? Once you turn 14 you can manage your own, you can invite your parents and carers to be nominated, representatives but you're allowed to manage it yourself from 14 on. So my health record is where your information is held and other health professionals are able to access that. What that means for us is that it can mean that you're digitally connected, you can access your online information when you need to using your phone or computer, your records can travel with you, if you're moving to another area that record is

still there and you can access it then. You don't have to be sick they say to benefit from it. You can also take things off your record if you don't want them available for everyone. So you can have quite a bit of control, I find when we most use it in the clinic is within a new patient is coming to our clinic and we're trying to access scans that have been previously done so that we can see where they're up to with their health care needs, and I use it quite a bit when checking and getting the health information to kind of make your first appointment with us as good as it can be and not wasted on trying to chase results and things that we might require. So for patient with Neurofibromatosis 1 the annual review is, there's a handout that we have and this is part of that hand out which looks at what the areas of interest are. This is a little bit small, it looks at the children's checklist from zero to 18 and for time I'll just let you look at that yourselves later. That's the adult one.

There are helpful apps medisafe and flare down, they store information about your health, there's medical alert that has information about, comes up on the front of your phone if you're in an emergency situation, in summary. I like to think transition care is a bit like learning to drive. When you start out learning to drive you start out slowly, you've got somebody beside you who is giving you instructions, maybe a parent or driving instructor and you practice and practice and you get better at it and eventually driving becomes automatic and eventually you will be driving your own health care. Eventually you will be taking charge of your health care. There will be some patients due to intellectual disabilities will never get total control but we like for everyone to have a degree of control over their care, keep calm, learn to drive your health care.

MONA: Thanks, that was fantastic. I had one question, with NF, for Jane, are you still there Jane?

JANE HO: Yes I'm here.

MONA: Do you have any contact with the NF clinic at North Shore hospital? For want of a better word, provide some sort of a discharge summary for the adult service because that's the only adult NF clinic I'm aware of in Sydney. =We know a little bit about the one in Melbourne; we had a presentation at our conference last year. Is there any co-ordination between the children's NF clinic and the adult one.

JANE HO: Well we don't usually attend the NF clinic because on the adult side our agreement with ACI is that they will do it. So in fact the person who covers north shore and also western area of New South Wales her name is Louise Charlton. Could be that Louise will come over to the Children's Hospital, next door at, Fabienne I'm sure you've met Louise. As far as handing over a summary of care, certainly ask the paediatric teams who are involved to do it because it's a good idea and gives that proper hand over that is needed.

MONA: That's great, I guess having this webinar will empower the young adults to take on that, their on voice as you

said, having their own voice is so important and maybe helping with that communication.

JANE HO: Fabienne brought up such a great point about using technology, to help with chronic disease management it gives people power to have that information about themselves.

MONA: A lot of the adults that are currently adults with NF often have communication difficulties and some don't even have a smart phone and I'm just wondering, do you have any ideas of how to re-engage those people in the community who are perhaps being cared for by a parent who have not benefitted by having interventions for their learning, and so by the time, now they're sort of in their 40s, and 50s with significant learning disabilities, the parents themselves are worried about what will happen to their adult child with NF. Other than sharing the guidelines with their GP and hoping to reconnect them with the clinic is there anything out that you're aware of for older adults with chronic conditions?

FABIENNE: Mona maybe I'll start answering that one. I think they should look at getting the NDIS set up for their adult child who's requiring care at home. Because in those packages they can identify, I think they should get a case worker or a management person to help guide them through what services they might need and can get in place and definitely they could ask for things like social, their adult who they're caring for to go to social outings together. If they've got some intellectual or mild intellectual disabilities where they can't engage in the community and there are services where they will be picked up taken out on a picnic or taken shopping in the community I'd definitely start there, I don't know Jane if there are other things you want to add.

JANE: I think it is hard, a hard question, I think there are increasing recognition of how to help support adults who have some impaired communication or intellectual disability, not mainstream. I think one of the important things is work out if that young person can't consent or communicate for themselves who can do it on their behalf and if they have any capacity to do that, usually it's the parent who is still involved but sometimes it may not be, so working that out is really important. So could be with regard to their health care decisions, could be with regard to their financial decisions because that person will still be having an income probably through the disability support pension. What are the legal ramifications of that, if that person is living at home with their parent, there's not disagreement about the health care decisions. It may be they don't need to go through any legal channels, everybody is agreed and hospitals and health care professionals would be happy to take on a parent who is acting on behalf of that adult, but sometimes if people don't agree and these things can change at any time of life. That's a different situation to consider those and troubleshoot those things would be important because these can cause a lot of stress and angst and think about - the guardianship tribunal is one, that is set up to particularly make decisions for adults in these cases. It may be that the guardianship tribunal awards that decision-making capacity to the parent but it may not, there's also somebody called a public guardian, think about things like that if they don't have capacity. If they're in their 40s already that issue will have been worked out. There are different areas and on our website we have an information sheet to support the transition of

those young people with intellectual disability, doesn't cover the 40-something year old adult.

MONA: While the apps and online connections are fantastic not everybody is comfortable with that as an adult and there's a lot of fear around security with online health management, as Fabienne mentioned with the my health record.

JANE HO: It's Jane talking. There is a balance, if people have chronic and complex health conditions my health record is such an advantage, most people don't realise your hospital record is not shared between different local health districts. If you're getting in care from the children's hospital and you go to Royal North Shore they can't see the record and that's where it's so good. On the other hand as a person of any age it may be that - who knows about internet security, and all of that, and they may not want to have, if they're seeing a psychologist or psychiatric for management of anxiety or other things that's really confidential, and private health information that does not need to go out to everybody who is involved in that young person's care. It's how to have a balance but in general if you have a chronic condition it's very useful to be on my health record.

MONA: I guess like everything in health, never a one size fits all model. You need to take individual circumstances in to account obviously. Thanks again to our speakers.