

Supplementary Table

Theme/ Subtheme	Quotations	Participant Characteristics
Avoid repeat of past disruption		
Maintain disease stability	I've spent my life in hospital seeing doctors... I don't want to go through change of medications like in the past. I don't think my disease will [impact my future], but my medication will. That's what I'm worried about. There's always that concern in the back of your head. How is he going to be affected long term? is it going to come back? I'm hoping that they wouldn't change too much...sometimes I think they go in...fiddle with this and fiddle with that. [My daughter's] illness has been stable for so long. Let's not go changing stuff.	PM18 undergoing transition PM16 lost-to follow-up CM50s CF40s
Preserve adjusted personal goals	I was sitting there, and I was crying because [becoming a car mechanic] was something I really wanted to do. It was one of those dreams that was crushed. So, I'm doing my Bachelor of Business now and I want to in the future, open up a bookstore café... The thing now is with injections and the painkillers, I think I'll be okay There were some days where...I got so overwhelmed, stressed, especially when there's an emergency call and I have to see the doctor on my exam day at school. If [my son] doesn't look after himself, how can he do his dream? He has to look after himself first.	PF19 post-transition PF18 undergoing transition CM40s
Protect social inclusion	I think [my friends] see me as someone separate from that [the disease]. When they see me with it, they still see me. [Friends] don't really understand [my condition] to the extent that I would like... having someone your age trying to handle [the disease] with school, they would know what it's like to do that stuff too. If it [the support group] was somebody who I'd be friends with normally, I'd be friends with them anyway... People deal with [the condition] differently, especially a current disease like this. The locality where we are, it's very isolating. A few kids have a disability at school, but not the same as [my son]. I guess he struggles the most because you can't see it.	PM15 pre-transition PF16 during transition PM19 post-transition CF40s
Encounter a daunting adult environment		
Serious and sombre mood	You look at a children's hospital and it looks awesome, I was so scared that [the adult's] would be dark and gloomy. That's a big change, not having my parents with me all the time. But I think the biggest change is getting used to the environment.	PF20 post-transition PM18 undergoing transition
Discredited and isolated identity	I don't want [the medications] but if they're going to help me with the pain, I need them... Why do I have to prove that I'm sick when I've been in here for a couple of weeks? For me it's also about the people in the hospital and how they respect each other. When you have someone who is very uncomfortable and you have to talk to them for the rest of the day, you don't feel that connection. I think [the doctors] could explain things to me more because I don't know the questions to ask, really. Because I'm not educated enough.	PF19 post-transition PM18 undergoing transition CF50s

Fear of a rigid system	<p>It was scary booking appointments. I was afraid of rescheduling... how? What would I say?</p> <p>[The GP] was very reluctant to refer on. Then we got referred to an adult rheumatologist here [in this remote area], and they [said] straightaway 'this is out of my ballpark, I deal with adults'.</p> <p>I had to take a lot of time off and [work] made it very hard for me, even though I had lots of letters from doctors. Then you're too scared to ever take any time off ever again.</p> <p>I wasn't clear what the NDIS¹ [National Disability Insurance Scheme] was, [the differences with] the disability payment... and Austudy². As a young adult choosing to move, my financial support can only go so far. I didn't know what options there were and how she fitted what criteria.</p>	<p>PF20 post-transition CF40s</p> <p>CF40s</p> <p>CF40s</p>
Establish therapeutic alliances with adult rheumatology providers		
Relinquish a trusting relationship	<p>I've had quite singular care by [my paediatrician]. Everything has always been, "I'll check with [my paediatrician]" ...so quite a big reception point. I'd go into surgery with other doctors and he's always stick his head in.</p> <p>He goes through those important aspects of my life which makes me feel very comfortable that he understands what I'm going through, and willing to help me... He was like a second father.</p> <p>We're going through an emotional time because I feel like he's part of my family, like he's an uncle to [my daughter]. He's taken time out that he hasn't been paid for to really take care of the kids.</p> <p>[The paediatrician's] just like someone who knows you so well... I'm quite a confident person but it's quite a vulnerable side.</p>	<p>PF19 post-transition</p> <p>PM18 undergoing transition</p> <p>CF40s</p> <p>PF19 post-transition</p>
Seek person-focused care	<p>You're not dealing with just a doctor, it's a team here. [It's] good but there's a lot more people that have a say in what's going on.</p> <p>Sometimes the doctors, just want to get things done and you don't really want to interrupt them.</p> <p>I do know [my daughter's] a bit hesitant and he's always busy when it comes to clinics...She just needs to assert herself and gets what she needs, because she doesn't look sick.</p>	<p>PF19 post-transition</p> <p>PF16 undergoing transition CF40s</p>
Redefine personal-professional boundaries	<p>It was very nerve wracking because... you don't know how close you are to your doctor that he's willing to let you slide in a few things, like if he needs to fill out this one form</p> <p>I'll just email him [paediatrician] and I know he'll answer. I know that most doctors aren't like that.</p> <p>I know how many patients doctors have. It's unrealistic to think that they'd know all [their patients] personally. I just hope he knows he's dealing with my most valuable possession.</p>	<p>PF20 post-transition</p> <p>CF40s</p> <p>CF40s</p>
Reassurance of alternative	<p>I didn't know everything that my mom knew [and] everything we needed to know. It was scarier than pressure.</p>	<p>PF19 post-transition</p>

¹ NDIS is a national agency that assists people with intellectual, physical and psychosocial disability access mainstream, community and informal support and services to improve skills and independence, funded by the Australian and state and territory governments.

² Austudy Payment is a Commonwealth national government funded payment providing income support to students if aged over 25, studying full-time and under the income and asset limits.

medical supports	[The adult rheumatologists] show[ing] they support and still have connections with their paediatric doctor would help. To know that if you feel uncomfortable, you're not trapped here and still have contact with your paediatric doctor.	PF20 post-transition
Natural transfer of trust to adult doctor	I didn't know much about hospitals [so] I didn't really want to have the say. [My paediatrician would] put me in good hands, with someone that he'd trust and he knows I'd like. I just assumed it [my history] would all be passed on, it would all be understood. I'm pretty confident that [the paediatric rheumatologist] will refer [my daughter] to someone he obviously trusts, because he's shown nothing but care and compassion towards her. I expect him to pass her onto someone as good.	PF20 post-transition PF18 undergoing transition CF40s
Negotiate patient autonomy		
Confidence in formerly gained independence	The doctors aren't going to chase you up, just like going from school to university. That's why it was so easy for me. I did the transition two years ago. Every time we saw him, he'd come back to the [transition] topic so it wasn't a one-time thing. He'd always talk about transition, not just "today we talk, now we transition". [My daughter's] a very mature person to begin with. She pushes advice away quickly. I notice that if I try and advise her too much, she'll just get distant, so I don't do that.	PM19 post-transition PF20 post-transition CF40s
Alleviate burden on patient	I am still believing [my son] will be able to [look after] himself. But as a parent we can't just walk away, you know?... That's why I still monitor him, encourage and support him... That doesn't mean I'm not going to look after him at all You know how you feel and the other person doesn't, but as a parent I can't drop the ball... I feel so sorry for him, and I wish the pain was mine instead of his. I have struggled quite a lot asking for people to do stuff for me, that's always hard for me.	CM50s CF40s P16 undergoing transition
Mediate parental anxiety	The whole thing [condition] was more stressful for my parents that it was for me the entire time... I feel like he's super obsessed with doing stuff because he just wants me to not be sick. [My mother] looks strong but she's soft. That's why I try to stay as healthy as possible because if anything bad happens to me, she'd over-react and get really sad. My child's not going to turn out 100% and they're going to have all this weight on their shoulders for the rest of their lives, if not a shortened lifespan.	PM19 post-transition PF20 post-transition CF40s
Abbreviations: P, patient; C, parental caregiver; M, male; F, female.		