M: Where do we start from Sean/[uses pseudonym followed by real name] (laugh)? Where do we start from? In the morning?

I: Yeah shall we start from when you wake up? What time for people waking up in the house?

M: Er mums always up first.

I: So your wake up time?

M: If I have had Sean for the night I am up by a quarter to five to do the first lot of medication.

I: Um hmm.

M: Which he has at five. Erm and then it will be come downstairs and wash the syringes out after that. Get the six o’ clock medications ready, go back upstairs, wait for Sean to wake up. He will wake up usually around six.

I: Hmm so early risers all round.

M: Oh well we are, the rest of them aren’t are they? They are lazy aren’t they? So then we are up, he is up at six, so we do the six o clock meds, change him, get your face washed don’t we? Do that bit first so you are all clean for sitting up. Erm and then he had to come down f and get all his IV bits because his IV is finished-

I: Hm hmm.

M: So that needs taking off and then prep his seven o’ clock meds. Erm so he will be sat up in bed probably watching SpongeBob or Topgear or something like that first thing in the morning.

I: Oh yeah.

M: Er I’ll have showered and be ready for work-

I: Hm hm.

M: Or if it is the holidays I will just be up and showered. Erm and then we get you washed and dressed if it is a school day don’t we? We start getting you properly washed, bed bathed and dressed at about twenty past seven. And then he is downstairs for eight o’ clock. We have to do another lot of medication for eight o’ clock before he leaves.

I: Hm.

M: Erm and then generally his bus is here at about ten past eight to pick him up. And then he goes off to school and I go off to work.

I: Yeah. What time is everyone else up? Are they… You said it was a bit later?

M: Er Daddy gets up sometimes six, sometimes seven, sometimes eight depending on where he has to be with his job.

I: Hmm.

M: Er Danny, we shout at Danny don’t we generally around seven o’ clock.

I: Is he sort of a real teenager then for getting up (laughs)?

M: Oh he is a real teenager. I can go in about four or five times can’t I? But he has to come down and get his medication done.

I: Hm.

M: Erm and then we are all out of the door. Danny is the same time as us usually isn’t he? We are all out of the door at about ten past eight. And then generally I am the first one back at about quarter past three.

I: Is your school quite local that you work at?

M: Oh bottom of the road.

I: Oh lovely.

M: It is literally bottom of the road in the church hall down there.

I: Yeah.

M: So it is ideal. Then Danny is back at about five to four. I come back, I have a cup of tea, run round with the vacuum cleaner if that needs doing or run round with the duster and then I start doing his medication and that, getting that ready. And then he is home about half past four, you come home on your bus don’t you?

I: It is quite a long day at school…

M: It is a long day.

I: With the travelling time included.

M: Yeah. It is a very long day.

I: Are you able to keep in touch with each other?

M: No.

I: So you just have the book at the end of the day from school-

M: Yep.

I: Telling you what has happened or…

M: I get a phone call, if there is anything they need to talk to me about they will always ring.

I: Yeah.

M: But generally we just, you come in don’t you, we read your diary, we take your stuff out, if there is swimming stuff that goes in the wash, then we sit down here and have a chat and then we take you upstairs do your five o’ clock meds, change you if you need changing and now its IV at five-

I: So that has changed has it from before?

M: So that's changed. They run for two hours and then his IV feed goes up at seven-

I: Hmm.

M: So…

I: So lots of different things-

M: Pretty much…

I: All the way through. Yeah.

M: If necessary in-between we throw you under the shower if it has not been a swimming day.

I: Oh yeah.

M: We might throw you under the shower. But weekends you have a shower don’t you? We get you up on a morning, chuck you under the shower. Which you have now started to be a teenager about.

I: (Laughs).

M: (Laugh). Yeah, somebody shouted at Mummy last weekend didn’t they?

S: Eeeeh ooh!

M: Yeah which he found incredibly funny.

I: Yeah (laugh).

M: Didn’t you?

S: Hmmm.

M: I called you ‘Danny two’ didn’t I?

S: Hmmm.

I: Picking up bad habits then (laughs).

M: Absolutely. But you didn’t win did you? I put you in the shower anyway.

S: Yeah.

M: So weekends still getting up the same time for me, obviously because the regime stays the same as it is in the week.

I: Um hm.

M: And then we go out don’t we? Walk into town or occasionally we will go down to Nanna’s or to Nonna’s. In the holidays we have got his trike at home from [School name] so we could go out on the trike.

I: Oh yeah. So are the family quite local then er…

M: Yes.

I: Just down the road or…

M: Nanny is down the road, Auntie Nicole, Uncle Sam and cousins are down the road and my mum is about a fifteen minute walk from here.

I: So you have got all the family in a very kind of close proximity.

M: Yeah. Yeah so we do that don’t we? Go to town go shopping. Sometimes we can go further a field if we have got someone who can drive your car.

I: What is town for you then?

M: Just into [Town name].

I: [Town name].

M: And if it is nice we will walk in and if it is not so nice we get the bus don’t we? But we always bus back because by the time we have walked round town, I have walked you in and walked you round I say no lets get the bus back. So you are quite well known on the bus aren’t you? All the drivers know you quite well. And of course a lot of the regulars on the bus know him quite well as well-

I: Yep, yeah I can imagine yeah that-

M: They always ask how he is doing. And then occasionally depending on what’s what we might go off somewhere else depending on, if someone else can drive us, because I can’t drive but his carers do and they are insured on his car-

I: Okay.

M: Which stays at my mum’s house erm because my mum’s partner and my mum bought it so we can use it as wheelchair accessible.

S: Eeeh, eeh.

I: That’s good.

M: But we have put his carers on the insurance so we might disappear off and go to [Town’s name 2], we go to [Town’s name 3], we’ve gone to [Town’s name 4] haven’t we? Done different things. So there is a lot-

I: There is a lot on your doorstep really for getting out for.

M: Yep,

I: Which is nice.

M: Yeah. And that is pretty much it isn’t it? Sundays tend to be a quiet day don’t they? Sundays, because he is at school all week and we usually go out on a Saturday, Sunday tends to be the chill out day.

I: Yeah.

M: So we just have a nice chilled out day on a Sunday don’t we? Sometimes you come and help out in the kitchen making food don’t you? You like making curry don’t you? Yeah.

I: (Laugh).

M: Extra hot curry don’t you?

S: Eeeh.

I: (Laugh).

M: So that burns him.

S: Eeeh.

M: You like making cakes don’t you? So er yeah we just decide on what he wants to do.

I: That is good. And erm so you said bedtime has changed now so it will be a bit earlier?

M: Yeah we (sigh) because we haven’t changed it when he has been at school we are hoping that when he goes back to school we are hoping that we can put the IV fluids up from six to eight and the TPM from eight until seven.

I: Hmm.

M: Erm but at the moment because we haven’t, we are not doing so much in the holidays it is going, we have brought it forward, so it is five till seven and seven until six, and then when we have a nurse overnight they take it all off for me in the mornings-

I: Okay.

M: So it is one less job for me to worry about.

I: Hmm.

M: So, isn’t it? But I have got you tonight haven’t I hey? So then for me that is a case of a mattress on the floor in his bedroom-

I: Yep.

M: Erm and listening out for any problems but I have set the alarms on all his machines and everything so-

I: So are you getting up at regular points in the night or…

M: I tend to set my alarm just to check on him-

I: Yeah.

M: But if any of his machines alarm it wakes me up.

I: Yeah.

M: And because he is on a ventilator at night I can hear his breathing, so if that changes believe it or not it wakes me up.

I: Hmm.

M: So once he is in a regular pattern it is fine but once it changes I am-

I: So you are just really sensitive to that sound?

M: Yeah very. So I obviously don’t go properly to sleep-

I: Yeah.

M: When I am with him. But we still manage don’t we? And then it is getting up at a quarter to five starting the next routine.

I: Yeah.

M: Yeah. So it is a long day, and it is a lot to do in the day, but we wouldn’t have it any other way would we hey?

I: Yeah. So there is a lot of time together and then a lot of time as well for (.) relaxing and…

M: Yeah. Yeah we are together a lot of the time aren't we? You don’t like me spending time with anyone else do you?

I: Hmm.

M: You become a green eyed monster don't you?

S: Hmm.

M: Yes match your green clothes.

S: Hmmm.

M: (Teasing/jokey laugh) Ha, ha, ha, ha. Yeah be honest.

S: Hmmm.

M: Yeah. You see last week I took Danny out. We took him to [School name] for the day, on Thursday, for the holiday club.

I: Oh yeah.

M: And I took Danny off to [Town’s name 3] and he had the sulks at holiday club for about the first half an hour-

I: Oh yeah.

M: Because I had gone off to do something with Danny.

I: Yep, yeah.

M: But I’ve tried… it is really hard because I know that we love doing things together but Danny always misses out.

I: Yep, yeah.

M: I never, ever have any time for him so-

I: Yeah.

M: It was a case of make the most of it while this one was at holiday club-

I: Yeah.

M: And try and have a day or a couple of days where we could go off and do something just so he got me... Because he got, this is what Sean doesn't understand is Danny struggles with it all as well.

I: Yeah, yeah.

M: So it is nice to get a bit of quality time just for him.

I: Yeah.

M: But you don’t like it do you? You don’t like sharing me. You go green.

I: (Laugh).

M: And then everyone laughs and goes, get over it! Don’t they? That is what they told you last week wasn’t it? That was what Sue told you, get over it! And she ignored you didn’t she and then you didn’t like that.

I: Hmm.

M: Then you snapped out of it apparently.

I: Well once you are there that is it you forget about it easily enough don’t you (laughs).

M: Well yeah that is why we do it.

I: (Laugh)

M: It is not like leaving him at home-

I: No.

M: Doing nothing you know.

I: There is a lot going on at [School name] I imagine.

M: Absolutely. Which was perfect timing for us, I mean it meant that we were on a short timescale really because by the time we had dropped him we got the half past ten train to [Town’s name 3] and then we had to come back at half past two well just after half past two.

I: Yep.

M: So it wasn’t like we had the whole day. It was very short lived. And what happened? Do you remember what happened? Danny chose something for you didn’t he? Funnily enough.

I: (Laugh).

M: Haven’t quite worked out why yet after you did your green eyed monster.

S: Hmm.

M: (Laughs) yeah. But he did pick something up for you didn’t he? In fact you are wearing them aren’t you? Your new trousers.

I: Very snazzy.

M: Yeah.

I: Yeah. Erm and the only other thing is just in terms of any kind of screen time and things. So we are interested kind of thing that, time you spend with a screen. So you were saying you have got the iPad.

M: Yep.

I: So you are quite a big film and TV watchers as well.

M: Yep.

I: So you have got Sponge Bob and Topgear in the morning.

M: Yep.

I: Are there any other times that are-

M: Evening time and time going to sleep.

I: Often screen time. Yep.

M: So that again could be Sponge Bob erm it might be the Simpsons if you really want to aggravate your mother.

I: Hmm.

M: Yeah (laughs). And that is just something that he will drift off to.

I: Yeah.

M: So that just makes it easier. Weekends we tend to sit and put films on don’t we? On a Sunday that is our film day isn’t it? We go through your dad’s collection don’t we and say, oh we haven’t seen this one have we, lets see what that is about. So that is definitely sit down time isn’t it?

I: And does the iPad get used much more than Skype and things or?

M: We have got a couple of games on there that you try and do, haven’t we? And emails and you do Facebook don’t you? You keep up with your friends and what is going on and message people.

I: Um hmm.

M: Yeah you quite like some of the games don’t you? There is a Simpsons one and a racing one.

I: Oh yeah.

M: Which he laughs because I am absolutely rubbish at it.

I: (Laughs).

M: And actually so is your brother, isn’t he? He thinks he is so clever but he can’t play it either so that makes two of us.

I: (Laughs).

M: So, and then your friend Gary comes sometimes doesn’t he? And then you play games on there with him. And you chat about football. Gary tries to come at least once a fortnight, doesn't he? And you have your boy time.

I: Oh yeah.

M: Don’t you? Gary is lovely, he is eighteen now or nineteen. But ever since his tenth birthday he started coming on a weekly basis and then when he got this new job, because it is shift work he can’t do it weekly so it is generally fortnightly.

I: Yeah.

M: But you like spending time with Gary don’t you?

I: It is nice to have someone come over and …

M: Yeah.

I: Spend a bit of time.

M: Yeah.

I: Just talk about things that are a bit more boy-

M: The boy things yeah. Mummy gets chucked out doesn’t she? I just do the boring stuff. I am only there to do your meds aren’t I? Gary does the rest. Doesn't he? He always stays for a few hours doesn’t he? He is coming to [Family centre name] as well isn’t he? Because he wants to swim with you doesn’t he? So we are going to try and get him down to [Family centre name] so he can get in the pool down there.

I: Yeah. He is quite a keen swimmer then Sean? Sean! Oh I called you Sean (laughs)!

M: Yeah you like your swimming don’t you? And I can’t wait to go swimming with you at [Family centre name], that would be good.

I: It is nice at [School name] kind of having regular time as well it is just-

M: Yeah.

I: Nice big empty pool…

M: Yeah.

I: Lots of space where…

M: Yeah well they have opened it up for families now.

I: Oh really yeah-

M: Which is really lovely. Um and you went on the 2nd of August didn’t you? Just after you came out of hospital. His carer took him unfortunately as I had an appointment up in London for a MRI scan on a Saturday, of all days, so I had to go up there and I couldn’t go to [School name] with him, but next time I am hoping to. They are starting to open it up on a weekend aren’t they? Which is really nice. Because otherwise a lot of us just don’t get a chance to swim with the kids.

I: Yep yeah.

M: Because you can’t take them to a normal swimming pool.

I: No, yeah.

M: Because it is too cold he can’t do, I mean when I say it is actually too cold for him-

I: No, yeah.

M: It needs to be-

I: A certain temperature.

M: It has got to be yeah.

I: Hmm.

M: Because it is too dangerous otherwise. It can cause you to have a fit can’t it? And we don’t want that obviously in the water so we can’t take you to a normal pool. So there are very few and far between that you are actually able to take them to so...

I: It is just nice to have the facilities opened up.

M: Definitely. I mean [Family centre name] you can if you ring and book but then because I don’t drive it is finding someone to do the drive to Chestnut and back.

I: Yep.

M: And it is a long way to go.

I: Yeah.

M: Just to get in the pool for half an hour. Whereas [School name] is only just up-

I: The road yeah.

M: And that is like only a ten-minute drive compared to a forty or fifty minute drive.

I: Yeah.

M: It is much better isn’t it?

I: So back at school is not so bad if you are just going back for the swimming rather than-

M: No I had not thought of that-

I: Lessons (laugh).

M: Because I have never swam in [School name]’s school. I think it will be quite nice. It will be good. So that will be something else we will be able to do on weekends, to put in the equation won’t it? And then you will have a shower after swimming so then you won’t have to go in the shower at home! How about that? He says, Mummy it is still water and I have still got to wash.

I: (Laugh).

M: And I am still allergic.

S: Eeeh (laughing).

I: (Laughing).

M: (Laugh) Yeah okay. (Sigh) well still got your wicked sense of humour haven’t you hey?

I: Great, okay.