

Laura



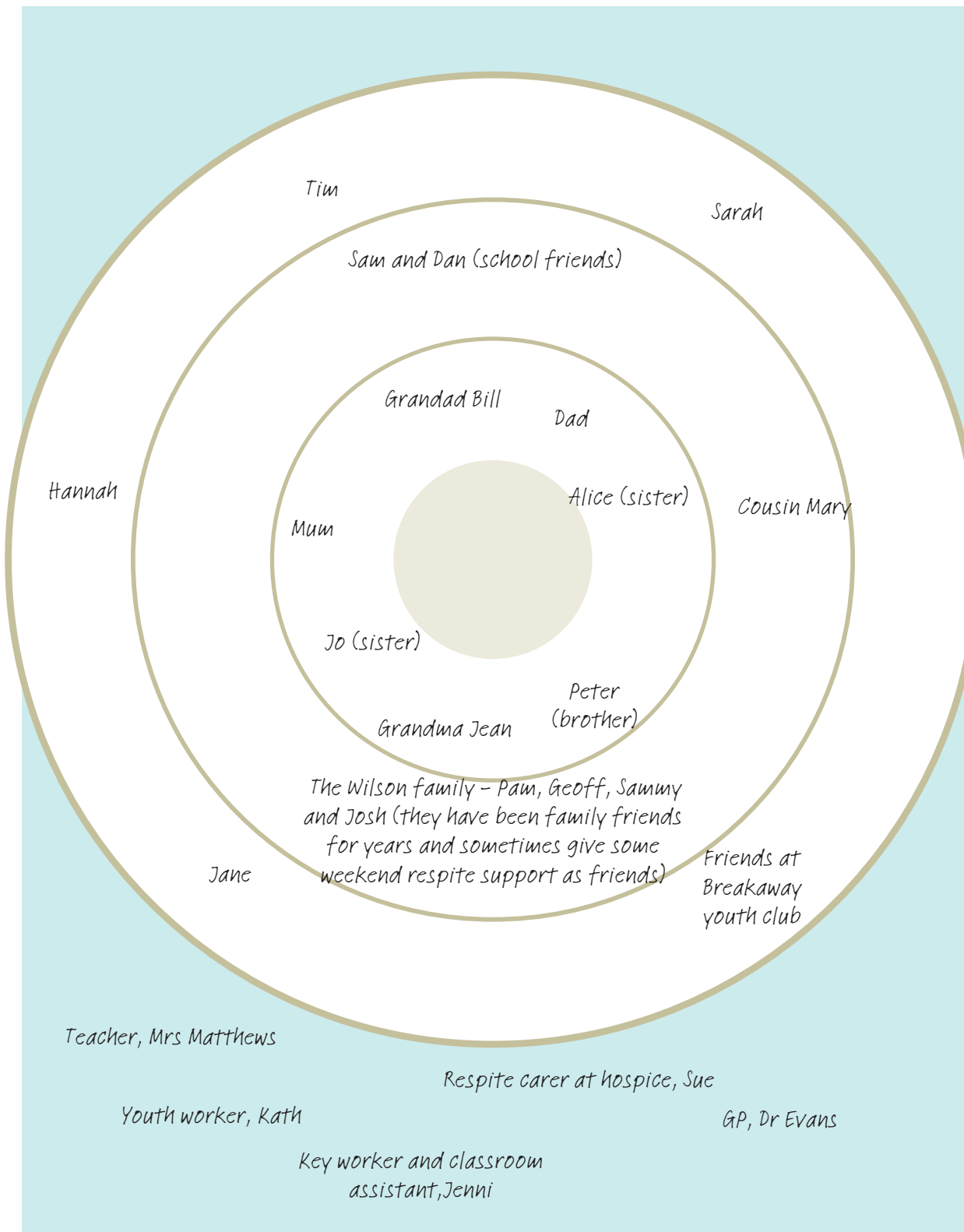
Laura is 16 years old. She has a sunny personality and a beautiful smile. She enjoys family life and is most relaxed when in familiar environments. She has a diagnosis of Sanfilippo. This syndrome is an inherited disease of the metabolism that makes the body unable to properly break down long chains of sugar molecules. It is a degenerative disease. The life-span of an affected young person does not usually extend beyond early twenties.

Laura lives at home with her parents and younger sisters, Alice and Jo and younger brother, Peter. She loves spending time with her sisters and loves to go to visit her Grandparents (Grandad Bill and Grandma Jean) and spending time with close family friends, the Wilson family, who she has known all her life. Laura loves having fashionable clothes and likes anything pink and fluffy - particularly when it comes to slippers. Her brother, Peter, has the same diagnosis as her. Laura's sisters both help their parents care for Laura and Peter. She and her brother attend a special school. Laura has nearly reached her 17th birthday and her parents are very worried about her transition to adult health, social and education services.

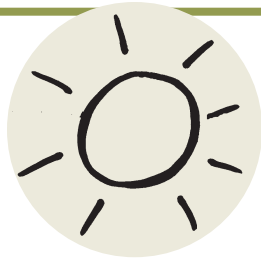
Laura initially developed like other young people her age. Her acquisition of speech was quite slow and incomplete. She has severe learning disabilities. Laura is moving into the final phase of her illness, this means her muscles are slowly getting weaker. As time moves on it is likely that she will become increasingly immobile and unresponsive. She is already using a wheelchair when she is out and about as she finds it difficult to walk very far. Laura has also begun to have some swallowing difficulties and does experience occasional seizures. She now needs help with all areas of her daily living, such as washing, dressing, eating and going to the toilet.

Laura and the family have support from a number of services including the GP, a paediatrician, a special school, a social worker from a disabled children's team and a children's hospice. She has had a few reviews at school and transition to adult services has been discussed, supported by her key worker. The Wilson family are friends and give some voluntary respite support to the family.

Thinking about relationships - Laura



What does a good day and a bad day look like for me?



Slept well. I wake feeling refreshed.

Mum wakes me up with a smile.

Lots of family noise in the house. The radio is on and Mum is singing. I can hear my family chatting to each other.

Mum and Dad help me get dressed and washed.

Plenty of time for breakfast and help from my sister (Alice). My favourite breakfast is Weetabix with warm milk. Yum!

Transport comes for school on time. It is sunny outside.

My friends Sam and Dan are smiling and chat to me.

I have music at school. My teacher is happy. She does interesting things and we play percussion to the music.

I have pasta for lunch.

Transport home from school drops me off first.

Home is busy my brother and sister have some friends round who chat with me.

We have big family tea.

All is peaceful at home- Mum and Dad are happy (if My Mum and Dad are cross or tell me off it upsets me).

I go to sleep quickly and peacefully after my sister, Alice reads me a funny story.



I have a restless night. I am not feeling very well as if I am getting a cold.

Mum is tired and is quiet and grumpy. She was up with me in the night.

I do not want to help as I am dressed and have a wash. I did not sleep well and I am tired.

I do not enjoy my breakfast and push my food away and throw it on the floor. I don't enjoy my food when I am feeling off colour. Mum gets a bit cross with me.

School transport arrives late and I have been waiting in my wheelchair for ages.

I do not want to be at school as I would rather be at home when I feeling tired or poorly. I do not want any drinks or food because I am feeling off colour.

My school friends are making lots of loud noises, they are shouting and laughing and I don't like too much shouting.

I get upset and I cry, scream and shout because the noise is upsetting me.

When I get home I remain unsettled after my challenging day at school. When I feel upset I do not help with anything I am asked to do and I often have a temper tantrum as a result.

I do not want to help when mum changes me into my pyjamas and I shout at her and push her because I am feeling upset.

What is important to me now, and how I want to be supported

What is important to me...

- My family – My Mum and Dad, my sisters Alice and Jo and my brother Peter.
- Grandad Bill and Grandma.
- My wheelchair to get around.
- People being happy and talking to me (not ignoring me).
- Food that I enjoy and that I can swallow without too much difficulty. Apple crumble and custard is favourite!
- That I am not rushed whilst I am eating a meal as I can find it difficult to swallow and I get indigestion and feel uncomfortable. I enjoy taking my time.
- Having a chat with whoever is helping me eat my meal. I love to talk about the soaps and football.
- I love having a shower or a bath. When I have a shower I really like the smell of Original Source lemon shower gel.
- Looking good! Wearing lovely clothes and makeup. I especially like pink.
- Comfortable pyjamas and slippers at night (pink please!)
- I enjoy listening to music– especially ABBA.

How best to support me...

- Those who help me need to know how I communicate and use approaches that I can understand such as Makaton.
- I use Makaton to communicate when I need food, drink or want to go to the toilet. See Laura's communication chart.
- Please always tell me what you are going to do with me before you do it.
- Give me clear and simple information.
- Involve me in discussion and decision making, I like to be part of the action.
- Give me plenty of time to eat my meals as I find it hard to eat and swallow and I cannot rush.
- Make sure I help chose my clothes. I know what I like.

How I communicate with you

At this time	When this happens	We think it means	We need to do this
<p>During the day at school or whilst staying in residential respite care.</p>	<p>I scream very loudly and sometimes I hit out at people around me. I may also bite or push people. I become hyperactive or unsettled. I will not stay still and sometimes I rock to and fro.</p>	<p>Frustration or anger. This often results from being misunderstood and this seems to happen more in unfamiliar environments.</p>	<p>Stay calm. Give verbal reassurance using Laura's name. It is best for Laura if familiar people are with her. Do not crowd around Laura. Create some space. Remove breakable objects. Keep other children and young people at a safe distance.</p>
<p>During the night.</p>	<p>I have sleep disturbances, I am restless and thrash around or scream during the night. I sometimes shout out and cry in my sleep, as if I am having a nightmare. I get very restless and throw my covers off. I often wake up in the night and don't easily go back to sleep.</p>	<p>This usually happens if I am overtired or experiencing pain or feel unwell.</p>	<p>Sit on Laura's bed and chat reassuringly to her. Sometimes playing music such as ABBA can help Laura to settle.</p>
<p>During school time or when I am in residential respite away from home.</p>	<p>I point at my card with Makaton symbols it means I want something. I will often use this card when I want a drink, I am hungry or I want to go to the toilet. I will also use Makaton to let you know when I would like to watch TV and if I want to go to bed.</p>	<p>I want to tell you something or I need help with something.</p>	<p>Try to understand what it is that Laura wants. Need to ensure there are teachers and helpers at school and in the hospice who can use Makaton and know when to offer help particularly with eating, drinking and going to the toilet. (Laura responds particularly well to , one of the classroom assistants in her class and to Kath, her Youth worker. They are able to understand Makaton and anticipate/respond to what she is telling them well).</p>