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Down Syndrome

Current Perspectives

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LIFE WITH AND FOR A PERSON WITH DOWN SYNDROME

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Introduction

This chapter will present and explore everyday issues that families may experience when one of them has Down syndrome. It is written by Down's Syndrome Association (DSA; England, Wales and Northern Ireland) staff who regularly talk to families face to face and via the helpline. The DSA aims to create opportunity and encouragement whereby children and adults lead fulfilling, good quality and healthy lives. We hope it will enrich the lives of all health professionals and inform their practice.

New parents

Walking in a new parent's shoes

Like any new parent, parents of a baby with Down syndrome will have questions. Families need factual information (not unrealistically positive or unduly negative) about their child's condition and not unhelpful predictions about a child's future based on outdated stereotypes.

Right from the start—giving the news—getting it right

Reflecting on their experiences of being told that their child has Down syndrome, parents overwhelmingly say that they would have preferred to have been told as soon as their health professionals' suspicions of Down syndrome arose.

> *I could tell the midwife was worried about something. When I asked her what it was she was very vague and dismissed me. By the time (the next day) when the consultant told us of their suspicions, I was relieved that it was only Down syndrome; I was expecting something much worse!*

But they wanted to be told when together (if both parents are involved) and at an appropriate time.

> *I was told my baby may have Down syndrome while I was still being stitched following delivery!*

They asked if they could have a word with me in private. I left my baby with my sister and they told me on my own in a side room. I just don't believe you should be given this news when you're on your own.

It is important that privacy for the new parents is available at the actual time of the disclosure.

I was there on the ward in front of all the other mothers when they told me, and without my husband. I was very emotional and embarrassed; I didn't know what to think or feel.

We were immediately whisked away to a side room and left there. I felt completely excluded, and like we were being judged because our baby wasn't 'perfect'.

Each new family is different. After the disclosure, health professionals should talk to the family about their needs. Some parents feel much more comfortable in a private room. Some parents may feel they do not want to be treated any differently from other parents.

A good start—what does a good model of communicating the news of diagnosis of Down syndrome look like?

New parents will usually need time to readjust to the news that their baby has Down syndrome. This is probably not what they were expecting to hear. People will react in many different ways. Times are changing; people with Down syndrome are much more visible and are valued and included in their communities. It may be that the new parent already knows someone with Down syndrome. Do not assume that parents are going to react negatively. Good disclosure can go a long way towards allaying parents' fears and helping them on their journey to accepting and loving their new baby.

Are you the right person for the job?

The disclosure should be made by a paediatrician, with up-to-date knowledge about Down syndrome. This should preferably be in the presence of a midwife who has had contact with the parents. Try to keep the number of people present to the minimum; any more than two people may be overwhelming for the new parents.

Preparation

Before you to talk to parents about their baby's condition, it is vital that you have read up-to-date information about living with Down syndrome. The Down's Syndrome Association (DSA) is a useful resource; take a look at their website or call their helpline (see Resources). The DSA can send you hard copies of their new parent information. Parents generally prefer hard copies to photocopies or copies that have been downloaded and printed. Some parents may feel that being given a photocopy or printed copy is second best; that somehow a value judgement is being made about the worth of their new baby. Ensure that you have the DSA's contact details to hand and information about the local Down syndrome support group

contact. Offer to put the parents in touch with another local parent with a child with Down syndrome. If the baby has a heart condition, the Down's Heart Group (see Resources) is a good source of information and advice.

I got in touch with the DSA when I found out and they put me in touch with my local group which was a great support to know that I was not alone.

It may be the first time you have had to talk to new parents about Down syndrome or it may be a number of years since you last saw a baby with Down syndrome. It can be helpful to discuss what you are going to say with a colleague; use them as a sounding board.

It is also important, as it is before talking to any new mother, to read through the mother's maternity notes to gather any available background information regarding the mother's circumstances, for example, previous children or social situation, as this may influence the amount of additional support that the family may need.

Environment matters

Make sure the room where you intend talking to the new parents is suitable, private and that other people will not be coming and going. Ensure that there will be no phone calls or interruptions.

Telling the parents

It is really important to tell both parents together whilst the baby is present. If the mother is single or the baby's father cannot be present, try to ensure support for her through a family member or friend. If English is not the parent's first language, have an interpreter present. It is important to brief the interpreter prior to speaking to the parents.

New parents want to be congratulated and told that they have a beautiful new baby. It really helps the process of readjustment to 'normalize' the situation. Some babies with Down syndrome will have immediate presenting health problems which require intervention. For parents of babies who are unwell, their baby's health will be the overriding concern with the Down syndrome taking a back seat—thinking about their child's Down syndrome will come later. All new families need to know that first and foremost they have a baby with the same needs as any other baby. The needs of a baby with Down syndrome are similar to any baby; they need to be fed, kept warm and clean and need nappy changes, comfort and plenty of cuddles. Their baby is a unique individual who will have more in common with their family than with other people with Down syndrome. Encourage the parents to get to know and enjoy their new baby. Reassure them that they do not need to be doing anything special or different at this stage. Their baby's needs are likely to be exactly the same as any other baby.

Do's and don'ts

- Language is really important—The baby *has* Down syndrome; he or she does not suffer from it. It is not a Down syndrome child or even worse, a Down child!

- Offer a balanced view of life for people with Down syndrome.
- Be realistic about the wide range of possibilities.
- Do not recite a list of all the possible health problems that a baby with Down syndrome might have. Be positive about the fact that we know what some of the more typical health issues are and that baby will be screened for these health issues in the coming weeks.
- None of us has a crystal ball; do not attempt to predict the future!
- Do not give a list of all the things that the child won't do or achieve.

Give the parents time to absorb the information and to ask questions; it is important not to rush through disclosure.

First questions

Receiving unexpected news may mean that new parents need a little more time to process what they are being told. Some parents may have a good or basic understanding of the condition already; others may have never met anyone with Down syndrome or have vague memories from their childhood of someone with Down syndrome in their neighbourhood living with elderly parents.

What type of questions do parents ask?

- What is Down syndrome?
- Why did this happen to us?
- Do we have a greater chance of having another child with Down syndrome?
- What are we dealing with?
- Can they tell me what level of intellectual disability my baby has?
- Is there any connection between the level of physical characteristics and level of intellectual disability?
- What are some of the health issues for children with Down syndrome?
- What are the differences about living with a baby with Down syndrome?
- Will my baby be able to breastfeed?
- Do I need to be doing anything special/different?
- Do I need early intervention immediately? I am worried that my baby is missing out.
- What shall I tell my baby's siblings about Down syndrome?
- Will the confusing and negative thoughts that I have about my baby go away?
- Do children with Down syndrome go to ordinary schools?
- What difficulties do children with Down syndrome have?
- Will people stare at my child?
- Will my child have friends?
- Will my child leave home?
- What do adults with Down syndrome do? What are their lives like?
- Will my child have relationships and maybe get married?
- What will happen to my child when I am no longer here?

Many answers to these questions are covered later in this chapter. If the parents ask a question and you do not know the answer, be honest and tell them you will find out. Take the parents' lead; check as you go along that they have understood what you have told them. It is up to your judgement but it can really help some parents if you interact with the baby, call him or her by their name and show your acceptance of their new baby. Before you leave, arrange a follow-up within a few days.

Health assessment

All babies with Down syndrome should have the same health checks as any baby. In the UK, this includes a physical examination, neonatal hearing screening and a blood spot test (importantly including TSH). Additionally, they should be screened for medical conditions more commonly present in Down syndrome (Charleton et al. 2010, 2014). Although parents should not be given an extensive list of the possible medical problems, the symptoms of the commonly associated conditions, for example, congenital heart disease and gastrointestinal problems, should be discussed.

Congenital heart disorders are present in up to 40–60% of babies with Down syndrome, but signs are not always apparent at birth. An initial assessment before discharge should be made along with arrangements for specialist cardiology assessment within 6 weeks (see Chapter 8). Malformations of the gastrointestinal tract usually present clinically. The eyes should be checked for cataract. With an increased risk of blood disorders (see Chapter 12), newborns with Down syndrome should have a full blood count. Management of most health conditions in babies with Down syndrome is the same as for the general population.

Feeding

New mothers, particularly if it is their first child, can find feeding a source of worry. They should be supported to feed their child by the method of their choice. Breastfeeding as for any baby is best; however, some mothers may choose not to breastfeed or find that because of their circumstances breastfeeding is not right for them. Feeding a baby with Down syndrome can be harder and needs more time, patience and perseverance. In addition, some babies may not be allowed to feed due to medical reasons. About 10% of babies with Down Syndrome may have an associated gastrointestinal malformation that requires a surgical intervention. They may need to be given nutrition intravenously.

Babies with significant congenital heart disease may be unable to feed because they are tired or breathless. They will be fed milk by a nasogastric tube till they are well enough to be fed by the method of their mother's choice. As babies with Down syndrome commonly have low muscle tone, symptoms of gastro-oesophageal reflux are common and should be managed appropriately (see Chapter 13).

Almost all mothers who want to breastfeed or to provide breast milk for their baby with Down syndrome can, with appropriate support. Some babies are not able to breastfeed fully at first, but as they grow older their feeding usually improves and then they are able to be breastfed fully. Mothers of these babies can express breast milk by hand or pump to build up their milk supply. The DSA's New Parent booklet contains guidance about breastfeeding.

Babies with Down syndrome may be slower to regain their birthweight and this may take up to a month. It is therefore vital to use Down syndrome-specific growth charts to monitor growth (see Chapter 10).

Support in hospital after giving the news

If possible, mothers should be offered the option of moving into a single room. Partners should be offered somewhere private to make phone calls and arrangements made for them to stay overnight should they wish. If possible, encourage all relevant staff to visit the mother regularly and interact with the baby by name. It is important to talk to the parents about what will happen next to reduce any anxieties they may have. It is helpful to inform the baby's General Physician, Health Visitor or Community Midwife of the condition.

Leaving hospital

Ensure that parents know with whom and how they can make contact, if they have any concerns about their child's health. An explanation should be given about local service provision for children with Down syndrome and follow-up arrangements should be clearly discussed. Ensure that they have all the contact information that they need for the future. In the UK, the parents are provided with a copy of the Down syndrome-specific inserts for their child's personal child health record (PCHR UK), including the Down Syndrome-specific weight and growth chart inserts (see Chapter 10).

Why is good communication around the diagnosis so important?

Understanding the impact of your words

Some parents say that the moment that they received the diagnosis remains crystal clear in their memories for many years. It is important to think about the words that are used when delivering the diagnosis. Speculation about how a child may turn out is not helpful to parents.

> *Well, it's lucky you live by the sea, as Down syndromes make excellent deckchair attendants.*
> *If you're lucky, she'll walk by the time she's 5, and be out of nappies by 7.*
> *Don't expect him to go to university or anything.*

Parents who are told about their baby's condition in a caring way and who feel supported in the early days may find it easier to accept the diagnosis.

> *A new dad called the DSA 2 days after his partner gave birth to their first child; a baby girl with Down syndrome. He said that he felt 'a bit shocked' but he wanted to find out more and to speak to local parents. He felt that the way he and his partner had been told the news had made a big difference; he described it as 'good, honest and open'. He finished the conversation by saying that he and his partner were 'eager to enjoy their daughter and were trying not to look too far ahead'.*

The way in which a diagnosis is given may influence the manner in which a parent interacts with, and perceives, their child for many years into the future.

A mother of a 7-year-old little girl with Down syndrome child called the DSA to discuss her daughter's behaviour at mealtimes. It transpired that at every mealtime the girl was throwing food whilst her siblings were expected to sit at the table and behave appropriately. The little girl's siblings had told their mother that they had had enough. After ways of changing this behaviour were discussed, the mother said 'I have never talked to anyone about my daughter's Down syndrome'. The mother described the negative things that she had been told by the health professional who diagnosed her daughter's Down syndrome. The mother left hospital with very low expectations of her new baby daughter. The mother did not want to talk to anyone about her daughter or to meet with other families. The low expectation of the mother meant that she accepted her daughter's generally poor behaviour as normal.

Each parent will react differently on hearing the news that their baby has Down syndrome. Because of greater awareness of the condition, some new parents may not see Down syndrome as an issue. They may know people with Down syndrome in their community. Their other children may have a classmate or friend with Down syndrome. It may take some families a little longer to accept their baby with Down syndrome. Some families may react with sadness because they wanted their baby to be like most other babies. They may be scared that they will find it hard to look after their baby. They may not know anything about Down syndrome. This is where health professionals can help in providing accurate and up-to-date information about Down syndrome. Make sure that your department has an up-to-date stock of literature from the DSA. Let parents know that this literature is available if they want it. Many anxieties can be reduced with accurate information. Most parents will want this literature but some parents will feel that they cannot look at it until some time has passed after the diagnosis. Most new parents find that once the early stages are over and their baby becomes more responsive and engaging, a relationship begins to develop and the new arrival becomes an integral part of the family.

Help parents to focus on the here and now, not a frightening imagined future

It is natural when faced with an unexpected situation for new parents to worry about the distant future. Their worries may be based on an outdated understanding of what people with Down syndrome can and do achieve. Beyond the certainty that a baby born with Down syndrome will have a degree of intellectual disability and experience some developmental delay, there is nothing further a health professional can tell a new parent about their individual child. We now know far more about the difficulties that children with Down syndrome have and how we can help them overcome some of these difficulties. The intellectual disability affects a child's ability to learn compared with other children of their age—it does not mean they cannot learn. Children with Down syndrome learn to walk, talk and meet

other developmental milestones but often later than their peers. Many children with Down syndrome are being included in mainstream education where, if given the right support, they learn and thrive. The most important message to communicate to new parents is that children with Down syndrome can do and like the vast array of activities enjoyed by all children.

It is impossible to predict outcomes for any individual child when he or she is very young, but in general, children and young people with Down syndrome are achieving much more than they have ever done. In the past it was believed that there were many things that people with Down syndrome could not do, when in fact they had never been given the opportunity to try. Today the opportunities have never been greater, enabling many people with Down syndrome to lead rich and varied lives. With differing levels of support, people with Down syndrome are now leaving home, forming relationships, gaining employment and leading independent and active lives. Their quality of life, life expectancy and role in the community have been transformed as health care, education, support and opportunities have improved.

> *After coming to terms with the news that our son had Down syndrome we held a party—yes, that's right, a party! I knew many of my family and friends would find it difficult to approach the subject. We wanted to educate them as much as we could and let them know that we were proud of our son and we were excited about his arrival. I printed off basic information on Down syndrome, photos, a definition of trisomy 21, stories of children and adults with the condition and information about the support we had received.*
>
> *It's your baby! That is the most important thing to remember. They will require everything any other baby needs and just a little more. But they will enrich your life. Our daughter is now a major driving force in our family and we are now closer and more positive than ever. She is a bundle of fun and carries a lot of the family trait for inquisitiveness! She is a constant surprise and joy—and your son or daughter will be as well!*
>
> **What all children need to reach their potential—including those with Down syndrome—is Love, Opportunity and Encouragement.**

Key points

- Parents should be informed that their child may have Down syndrome, as soon as the diagnosis is suspected, by an experienced paediatrician with good knowledge about Down syndrome and living with Down syndrome.
- The news should be given in a sensitive, balanced and non-judgemental manner with privacy being maintained at all times.
- At the time of giving the news, the mother should be supported by her partner/family.
- The baby should have a comprehensive health assessment, particularly looking for conditions more commonly occurring in children with Down syndrome, for example, a specialist cardiology assessment for congenital heart disease.

- The families should be provided with up-to-date written information about the condition, for example, the DSA Information leaflet for new parents. In addition, they should be provided with information about the local parents, Down syndrome support groups and health service provision including contact details.
- It is vital to support parents appropriately along their child's journey to enable them to love and enjoy their new baby.

Developmental progress: the pre-school years

WHAT IS THE DEVELOPMENTAL PROFILE IN THE FIRST 2 YEARS?

The first few months involve adjustment to the new arrival and an emerging new set of expectations. Development in the first 18 months or so has at its centre the enabling progression of motor skills. Motor skills allow infants to start to explore the world. Infants first gain truncal support and balance. This frees up the hands to reach, grasp and explore surrounding objects. Crawling or bottom shuffling will then follow allowing the ambit of operations to spread. Increased tone and control then spread caudally as the young explorer then learns to pull to stand, coast and then walk. Low muscle tone often predominates in children with Down syndrome and curtails this process. It is frustrating for the child, parents and therapists. There are ways of reducing raised tone but you cannot put tone in where it does not exist. So, if the child cannot get to the world, parents and therapists have to bring the world to the child with due attention to toys and seating. Play can involve positioning to allow the child an opportunity to feel the weight of his or her body, so enhancing resting antigravity muscle activity. The other ingredient of success is patience. Children do not learn in a linear fashion. As they pick up any new skill they will be unreliable for it for a while, until they have consolidated that learning (demonstrated well later on when potty training; we call the result of this unreliability 'accidents'). The pattern for learning is one of spurts (new skill) and plateaux (consolidation). In children with typical development, the spurts and plateaux may not be so obvious but in a child with intellectual disability, the plateaux are much more obvious. Then, just when parents are becoming disheartened and feeling their child will never learn another thing again, a new skill suddenly appears.

In the second 6 months of life, imitative gesture appears (e.g. pat-a-cake). Then children can start attributing meaning to the gesture, which represents the emergence of language (e.g. waving good-bye, shaking the head for 'no'). The very fine motor control of tongue muscles required to produce the packets of sound that are interpretable by others as spoken language is too difficult at this stage for most children with Down syndrome. Simple sign systems such as Makaton, therefore, provide the mainstay of communication for the 2 years or so that follow (see below and Chapter 19). Social and cognitive skills appear alongside language skills and, typically, children with Down syndrome will develop in the low average range in the first 2 years of life.

Social and cognitive skills develop alongside language skills. Relationships and interactions with people in the child's life affect all areas of learning and development—social emotional, cognition, play, language and communication. Adults need to be highly responsive and understand the world from the child's perspective. Being animated, accompanying

communication with intonation, pointing and gesture, repeating activities the child enjoys, following the child's focus of attention and interacting on the same physical level will all promote development. Visual materials and motivating and interactive activities that incorporate modelling, copying and turn-taking encourage development in all areas. The work of Roberts et al. (2007, 2008) offers advice for speech and language therapists on interventions parents might use through a programme of daily activities to encourage receptive and expressive language and speech skills.

From the age of about 10 months, the developmental profile of a child begins to carry a broadly predictive quality. Children with higher developmental quotients will tend to keep that position, and the same applies to those with lower developmental quotients. Parents will often ask about what the future holds. Care needs to be taken in answering. If an assessment is done at the end of a plateau, it will serve to underestimate a child's ability; if done at the beginning of a plateau, it will serve to estimate ability. We have already stated that what all children need to thrive is love, opportunity and encouragement. We need to apply that knowledge to children with Down syndrome (this is considered more in Chapter 19). The information that follows is designed to inform readers about the *development of most but not all* pre-school children with Down syndrome. Figures 4.1–4.4 reflect the range of ability in children with Down syndrome in the pre-school years compared with that seen in typically developing children.

Development from 3 to 5 years

Between 3 and 5 years, most families will be enjoying seeing their children develop into active, mobile, interactive and socially engaging young people. They will see how their child with Down syndrome is progressing in a similar way to other children, albeit more slowly particularly in learning to speak. Most children will be communicating with sign language and will have begun to say some words. Families will face the same challenges as any family with a young child, with extra demands where children have additional health or developmental needs. As for any family, additional support may be required due to socioeconomic, mental health or relationship factors or where they lack a support network.

Doctors and therapists should work closely with parents to assess, support and encourage development. Most children with Down syndrome are good at learning visually and understand best by watching or being shown. They learn less easily from listening to spoken information. Interventions that enhance verbal and problem-solving environments throughout early childhood along with efforts to reduce negative, over pessimistic influences give cognitive development the best opportunity. Doctors and therapists should be sensitive to individual differences and parental concerns arising from comparisons with other children. The more difficult learning is for an individual, the more important it becomes to provide an education that takes advantage of the person's learning strengths and minimizes confrontation with learning barriers.

Communication

Between 3 and 5 years the majority of children will have developed joint attention skills, understand many single words and short sentences, be communicating in sign language and

DOWN SYNDROME–DEVELOPMENTAL MILESTONES

Finding out about moving

Activity	Children with Down syndrome		Typical Children	
	Average age	Range	Average age	Range
Holds head steady when sitting	5 months	3–5 months	3 months	1–4 months
Rolls over	8 months	4–12 months	5 months	2–10 months
Sits alone	9 months	6–16 months	7 months	5–9 months
Stands alone	18 months	12–38 months	11 months	9–16 months
Walks alone	23 months	13–48 months	12 months	9–17 months

Fig. 4.1. Developmental milestones in Down syndrome: Finding out about moving.
Reproduced from the Parent Held Child Record insert for babies born with Down syndrome (3rd ed, June 2011) with the kind permission of the Down Syndrome Medical Interest Group.

DOWN SYNDROME–DEVELOPMENTAL MILESTONES

Finding out about hands

Activity	Children with Down syndrome		Typical Children	
	Average age	Range	Average age	Range
Follows objects with eyes	3 months	1.5–6 months	1.5 months	1–3 months
Reaches out and grasps objects	6 months	4–11 months	4 months	2–6 months
Passes objects hand to hand	8 months	6–12 months	5.5 months	4–8 months
Builds a tower of 2 cubes	30 months	14–32 months	15 months	10–19 months
Copies a circle	48 months	36–60 months+	30 months	24–40 months

Fig. 4.2. Developmental milestones in Down syndrome: Finding out about hands.
Reproduced from the Parent Held Child Record insert for babies born with Down syndrome (3rd ed, June 2011) with the kind permission of the Down Syndrome Medical Interest Group.

DOWN SYNDROME–DEVELOPMENTAL MILESTONES

Finding out about words

Activity	Children with Down syndrome		Typical Children	
	Average age	Range	Average age	Range
Responds to sounds	1 month	0.5–1.5 months	0 month	0–1 month
Babbles "Da-da" and "Ma-ma"	7 months	4–8 months	4 months	2–6 months
Responds to simple instructions	16 months	12–24 months	10 months	6–14 months
First words spoken with meaning	18 months	13–36 months	14 months	10–23 months
2-word phrases	30 months	18–60 months+	20 months	15–30 months

Fig. 4.3. Developmental milestones in Down syndrome: Finding out about words.
Reproduced from the Parent Held Child Record insert for babies born with Down syndrome (3rd ed, June 2011) with the kind permission of the Down Syndrome Medical Interest Group.

DOWN SYNDROME–DEVELOPMENTAL MILESTONES

Finding out about people

Activity	Children with Down syndrome		Typical Children	
	Average age	Range	Average age	Range
Smiles when talked to	2 months	1.5–4 months	1 months	1–2 months
Plays pat-a-cake or peek-a-boo	11 months	9–16 months	8 months	5–13 months
Drinks from an ordinary cup	20 months	12–30 months	12 months	9–17 months
Dry by day	36 months	18–50 months+	24 months	14–36 months
Bowel control	36 months	20–60 months+	24 months	16–48 months

Fig. 4.4. Developmental milestones in Down syndrome: Finding out about people.
Reproduced from the Parent Held Child Record insert for babies born with Down syndrome (3rd ed, June 2011) with the kind permission of the Down Syndrome Medical Interest Group.

be increasing their range of vocalizations and spoken words. Children may now be able to request things they want, and ask for particular people.

Some children with Down syndrome show relative weaknesses in their development of attention, communication and play skills. In this case, interventions that teach parents to become more responsive in their interactions, to understand sensory differences and manage behaviour are useful. Similarly, they can benefit from appropriate augmentative communication supports (e.g. the Picture Exchange Communication System [PECS]).

Practice through everyday play, interactive activities supplemented by focused activities will extend vocabulary. As speech skills develop spoken language begins to take over from sign language between 4 and 5 years of age. Parents may notice spoken language increases during their children's first year at school. The neurology of speech and language development is dealt with further in Chapter 18.

Understanding and expression

Most children will show fairly good understanding in familiar situations and be easily engaged in social interaction. They will use non-language cues as well as their understanding of spoken language to follow instructions. The understanding of spoken language is usually less impaired than expression. They will usually be able to understand early vocabulary, including nouns for everyday items, animals, clothes, family, food, body, transport and so on; as well as verbs for daily actions; adjectives to describe colour, size, shape, quantity and personal qualities; prepositions 'in', 'on', 'under', 'up' and 'down'; and social words 'hello' and 'bye-bye'. Some children will understand many hundreds of words. Children will learn new vocabulary through daily interactions/activities as well as through targeted activities with repetition, practice and visual supports. Most children will understand/remember two key-word information but many will be less able. Remembering and understanding of sentences are affected by attention, motivation and listening environment.

Social development and behaviour

Most children with Down syndrome enjoy social interaction and can engage well in shared play and other activities. At preschool, they often need a high level of supervision and support for successful peer interactions and to teach new communicative behaviours as necessary. They nonetheless will develop friendships through shared activities and experiences with other children. Most pre-school infants with Down syndrome will not yet have the communication skills they need to express their feelings or to communicate about their experiences out of context.

Children with Down syndrome may develop challenging behaviours which are common behaviours for all children at a similar stage in development. However, the behaviours may continue for longer than usual and can become habitual, occasionally with longer-term consequences. Therefore, particular attention should be given to providing support for parents in behaviour management. Factors related to poor quality sleep, health issues, communication and play skills may contribute to the development of challenging behaviours in some children. There is also a risk that some children may be unintentionally rewarded for

inappropriate behaviours when these behaviours are responded to with social engagement; negative or positive.

Positive behaviour management approaches applied consistently work well. These include observing and recording behaviour, analysing the functions of the behaviour and agreeing a plan for behavioural change; preventing the behaviour from occurring, teaching new skills, rewarding positive behaviours and ceasing to reward unwanted behaviours. Children benefit from clear expectations modelled to them and illustrated visually. They will learn from their successful experience of following daily routines (with support as required) for the new demands of preschool/school.

Cognition and play

Most children between the ages of 3 and 5 years will have begun to play 'pretend' by acting out short familiar scenarios with dolls and other toys/props. Many children will probably still enjoy exploring, playing with cause and effect toys and may like moving items about from one container/place to another. Some children may be interested in playing with small world toys, particularly for known TV characters and will be able to copy a sequence of modelled play activities. Some may engage in solitary play for quite long periods in some situations, although in a busy situation, such as preschool, may go from one activity to another. Most will need a play partner to help maintain their own play, play alongside and engage with others in play.

Most will have an extensive knowledge of nursery rhymes, be able to match visually identical items (pictures, words, colours, etc.), build a small tower of bricks and have begun to hold a pen using an early tripod grip. With modelling, children may be able to draw lines up and down, make circular marks and dots. At around 5 years many children will be able to remove and replace felt pen lids, colour within a defined area (approximately) and be able to draw a face or person. Many will be able to do inset puzzles but may need help and support to do simple jigsaw puzzles.

Many children will have begun to develop 1:1 correspondence in counting tasks and count with support using a number line. Children may recite numbers out of sequence when they attempt to count objects one for one. Some children will have 'Numicon' equipment or similar visual number teaching materials at preschool and/or at home. If so, they will be learning to fill the board with shapes, match shapes, select and name shapes.

Children are likely to enjoy books and being read to. Many pre-school children will enjoy reading personal books about them and their families. Some will have been introduced to reading through word-to-word matching games and may be learning to read with published reading resources and apps.

Motor skills

Delayed motor skill development and small stature can affect children's mobility, balance, participation with peers and self-help and independence skills. Most children will need extra help to dress and undress themselves and access the toilet. The majority of children will be eating a range of finger foods, drinking through a straw and drinking from an open

cup by the age of 5. Physio- and occupational therapists can offer useful guidance but most parents will skilfully devise practical solutions. Therapists can, however, do much to improve confidence and self-esteem.

Toilet training

Between 3 and 5 years most children with Down syndrome develop toilet awareness and continence through a training programme at home and preschool, aided by wearing pants (not pull ups) and rewards. Parents and pre-school staff can choose a time for starting a toilet training programme as the date for starting school approaches.

Sensory and health needs

All children need their sensory and health needs addressed for optimal development.

Conductive hearing loss between the ages of 2 and 4 years affects both receptive and expressive language skills of children with Down syndrome (Laws and Hall 2014; see Chapter 5 on hearing and Chapter 18 on neuropsychiatry). This finding highlights the need for audiology and speech and language therapy services to address hearing combined with speech and language interventions through a proactive service. Children with hearing loss will benefit from optimal listening environments, reduction in background noise, people speaking clearly but naturally and gaining visual attention before starting to speak. A focus on listening skills/activities is recommended.

Vision

Parents, preschools and schools are advised that children with Down syndrome do not see as clearly as children who do not have Down syndrome. At preschool and later they will be helped by using black felt pens for writing, teaching and learning materials with good contrast and by being seated near the front of the class (see Chapter 6 on visual impairment).

Sensory differences

Some children experience additional sensory differences such as those involving taste, smell, touch, balance and movement (vestibular sense) and sensory information from their muscles and joints (proprioception). Sensory differences can have a significant impact on behaviour and communication. Parents, doctors and therapists, especially physio- and occupational therapists, can support children by making adjustments and providing activities that can help.

Sleep

About 80% of children with Down syndrome are reported to show some kind of sleep problem. These can be behavioural or physical in nature (related to sleep disordered breathing-see Chapter 9) or a combination. Sleep issues can cause considerable disruption to family life and the effects may be overlooked. Poor quality sleep may lead to irritability, overactivity and impaired attention and concentration the following day.

Common behavioural patterns include difficulty in settling, repeated night-time waking with demands for parental attention, early morning waking and insisting on sleeping with

parents. Commonly, the settling and night waking problems result from children never having learnt to fall asleep without their parents present. Establishing consistent bedtime routines, going to bed when tired, falling asleep without parents present and avoiding too much excitement near bedtime are some of the things that will help to improve sleep. These principles will work with persistence and a consistent approach. There are an increasing number of sleep clinics around the UK dealing with behavioural sleep problems pursuing these principles.

A physical cause may accompany a behavioural cause—or be the primary cause. Sleep-related upper airway obstruction should always be considered (see Chapter 9). Disturbed night behaviour may be part of a more general behaviour disorder or represent pain such as with an ear infection. It may be one of the very common harmless but disruptive sleep disorders. These include sleepwalking or sleep terrors, headbanging, night-time fears, nightmares and bedwetting. These events can mimic epileptic seizures which only very rarely would be the cause. Children with Down syndrome can be very restless sleepers and move around a lot during sleep.

Support for families: parents at the centre

Most parent carers will be accessing information and services to help support their child's development. They will be looking for guidance from doctors and therapists with knowledge about how Down syndrome may affect their child's development and interventions to address those specific needs. Some will be learning about ways to help their child at home and preschool by attending training events, belonging to a local parent led support group, or by being connected through Down syndrome social media networks. Many parent-led support groups provide early intervention services and speech, language and communication groups as well as social activities. Support groups provide an effective route for parents to share information. They create opportunity and encouragement. For well-informed parents, expectations for effective services and knowledgeable practitioners will be high.

Families have told us they want informed, positive practitioners who can provide relevant information and advice for their individual child. They want health practitioners to know about how people live with Down syndrome today, to have high expectations and to help them help their children. They will expect practitioners to use appropriate 'child first' terminology and be interested in their children.

> *Quote from parent:*
> *I am often told what 'they' can do. I am tempted to ask, 'Who are they, are you talking about my son? Will he do that?'. I want people to talk about my child by his name, to discuss his development and his needs.*

Health practitioners should be familiar with the Early Support principles, how to put children, young people and their families at the centre of coordinated and seamless service delivery; how to make informed choices; how to take the lead in decision making and become active partners in service planning, improvement and delivery (see National Children's Bureau, in Resources at the end of the chapter).

Going to preschool

Most children in the UK start preschool on a part-time basis during their third year. Most parents will be anticipating progression from a mainstream preschool to a local mainstream primary school. Children usually require additional support to meet their educational needs at preschool and are likely to be receiving a variety of services including speech and language therapy, sensory impairment, physiotherapy and occupational therapy services.

Supporting communication—home link books and conversation diaries

Parents and schools may communicate through two types of home–school communication resources: (1) 'Home–school link books' are for parents and school staff to share information about the child; and (2) 'Conversation' or 'communication' books help children to share their experiences through a daily diary, a type of personal book that goes back and forth between school and home. A support assistant or teacher finds out what the child enjoyed during the day. They then draw a picture or stick a photo into the diary, accompanied by a simple, personal sentence to explain the activity. Parents can add to the diary with images and words from the weekends or evenings for their child to share with friends and teachers at school. Some parents and schools use a tablet device for this purpose.

Recommendations for preschool

Children will continue to develop their attention skills, receptive language, play, early learning (e.g. matching, classifying, drawing) and social skills. They will be in the early stages of using language to express themselves, for both signed and spoken language.

Children will need guidance, support and tailored interventions embedded in their teaching and learning activities and daily routines at school to progress optimally. Most children will need additional support to help them succeed across the curriculum at preschool and later school.

Children will need a speech and language therapy service to provide a comprehensive programme for developing their communication skills, receptive language, expressive language and speech skills.

An occupational therapy service will advise school on seating, access to the toilet and activities to promote the development of fine motor skills, through the encouragement of daily living activities-skills that will continue to improve through enjoyable practice. A box of fine motor activities, use of large felt pens on a white board, easel activities and side-by-side modelling/copying will help most children to practise.

Children will need structured literacy teaching, including whole word and phonic activities, beginning with learning letters and their sounds, and graded book reading. Many can learn to recognize words, letters and sounds if they are taught how to do this. Children with Down syndrome can progress well in learning to read at school, so expectations should be high.

Children will benefit from a visual timetable to anticipate activities, helped by teaching them time words such as 'now' and 'next'.

In preschool and later school, making a whiteboard and pen available for an adult to draw pictures illustrating information for the child will help refocus the child's attention when required and support listening, understanding and remembering in group listening situations.

Most children with Down syndrome learn from their peers through observation and imitation. Therefore, children should be encouraged to work in pairs and groups at school, with the support to facilitate this.

The school years

The information below is as general as possible but is set within the context of families in England. Education systems in other countries may differ considerably.

Introduction

The aim for school-age children with Down syndrome should be the same as for any other child: to become happy and flourishing members of their family, their school and their local community. This is a realistic goal but can only be achieved by professionals working together with parents to ensure that the right support is put in place.

Starting school

It is important for parents to be prepared and plan ahead for their child starting school. Children in England now can start school in September after their 4th birthday, so parents should be thinking about school once their child is 3 years old. However, as children develop and change quickly in the early years, they will need to be flexible in their hopes and expectations.

Which is the right school for a child with Down syndrome?

There is no one size fits all answer to this question. The majority of young children with Down syndrome are educated in mainstream primary schools, generally in their local school alongside their brothers and sisters and children from the community where they live. Extra help is available for children with Down syndrome in mainstream schools.

Parents are always advised to visit schools, look around carefully and talk to the special needs coordinator in the school. The following are some questions they might want to ask:

- Is the atmosphere welcoming to children with different needs and backgrounds?
- What is the school's experience of children with special educational needs in general and Down syndrome in particular?
- Are school staff keen to learn and undertake training on Down syndrome?
- How involved are class teachers in teaching children with special educational needs—are children with special educational needs taught separately or with the whole class?
- Does the school focus exclusively on getting good results, or do they look at the progress made by all children?

- How do they manage behaviour—are they firm but flexible?
- How does the school communicate with parents?

The most important thing is an inclusive attitude and willingness to learn and to get to know the child as an individual.

Some parents of children with Down syndrome and more complex needs prefer them to go to a special school, as therapies and medical support are more likely to be available on site. There are no special schools specifically for children with Down syndrome, so they may attend a variety of schools for children with a learning disability. If the child has an additional disadvantage, such as autism or a visual or hearing impairment, that will need to be taken into account. For a special school, families may want to think about the following:

- What is the specialism of school?
- What sort of peer group would the child have?
- Are there good role models for behaviour?
- Are therapies and medical support available at the school?

Should children with Down syndrome be held back a year?

This is a frequent question from parents. Many parents of children with Down syndrome, in common with parents of summer-born children, may feel that their child is not ready to start school at the usual age and would benefit from an extra year in nursery. In England, children are assigned to year groups by chronological age. It is possible to be placed in a different year group but this is relatively rare and is generally only recommended where the child has perhaps missed out on nursery education for health reasons and would be very young for the year group. All schools have a duty to adapt the curriculum for all the children in a class, whatever stage they are working at, so children should not be held back because they have not reached a particular target. It is also important for children with Down syndrome to be with their age peers in order to have good role models of age appropriate behaviour.

Legal and bureaucratic

There are certain legal and bureaucratic hoops that parents will need to jump through to get their child into school and get the right help. One of the problems faced by families is that services do not always work well together and the right people do not know about the child at the right time. The DSA would always advise parents to be proactive and not sit back and expect things to happen. The DSA and similar organizations elsewhere can help by giving parents information to make sure that the right procedures are triggered at the right time.

Some school issues: primary school

How are children with Down syndrome supported at school?

Children with Down syndrome in mainstream schools are likely to be supported by one or more teaching assistants (TA). However, support is not the sole responsibility of the TA,

but should be a whole school matter. Ideally, all staff in the school should receive training in the learning and communication needs of children with Down syndrome. The child should take part in the life of the school along with his or her classmates. As social skills are a strength, children should be part of the normal class group, not be constantly taken out of the classroom. The curriculum will need to be differentiated according to the needs of the child.

To meet children's educational needs at primary school, schools need to have a positive attitude towards inclusion and whole school systems to support this outcome, with training for staff about the needs of children with Down syndrome and the use of evidence-based interventions. It will help schools and other practitioners to be aware of the evidence for the benefits of inclusion for children with Down syndrome who do not have additional or complex needs, following a model of full inclusion with a high level of individual support (Buckley et al. 2002; Fox et al. 2004; Turner et al. 2008). The support is likely to include the following:

- Developing self-help skills and personal care, including taking to the toilet,
- Developing play skills—using modelling and imitation strengths,
- Facilitating interaction with peers,
- Delivering differentiated activities under the guidance of the class teacher, particularly for supporting spoken information and listening activities with visual information—signs, gesture, pictures, written words, modelling and repetition,
- Providing daily speech and language activities, guided by the child's speech and language therapist,
- Providing short periods of additional, focused literacy and language activities, including a daily 'conversation diary', whole word reading and phonic programme,
- Providing focused numeracy activities, including use of visual supports,
- Providing practice for developing fine motor skills, guided by an occupational therapist,
- Modelling of drawing and handwriting activities for children to copy,
- Guidance to ensure that children follow routines at school (including using a visual timetable) and maintain positive behaviour.

Successful education will require a flexible approach with school and parents working in partnership.

Inclusion

Example of inclusion from the DSA leaflet 'Celebrating success—primary'
Conor is fully integrated into his class and participates in all activities to a level that he is comfortable with. He sits with his peers and interacts with them and his classmates are aware of his needs as well as his limitations. Sitting alongside his classmates allows Conor to improve his interpersonal skills and use his classmates as role models. He definitely follows their lead! There are clear expectations for on-task behaviour for all the children. Conor receives a great deal of positive attention and

his successes are celebrated both in the lesson plenaries and in the classroom displays.

Work is differentiated and personalized, and support and demands are varied. There is a good balance between Conor being unsupported as part of the whole class, working with his peers, receiving 1:1 support and being allowed to play independently.

Communication and Language

By the time they reach school age, most children with Down syndrome will have started to talk but may still be using sign language or gesture to help them communicate. Language and communication will continue to be an area where support is required. Schools should make use of visual strategies throughout the curriculum rather than relying purely on speaking and listening, as children with Down syndrome are good visual learners but often have poor auditory memory.

Most children with Down syndrome will require speech and language therapy to support their communication needs. In England, this is generally provided by the National Health Service (NHS) therapists going into school to observe and assess the child and monitor progress. A programme will then be drawn up, which may be delivered directly by the speech and language therapist in individual sessions, by school staff during the school day or a combination of the two. All speech and language goals should also be embedded into the curriculum.

Children rarely get as much speech and language therapy as parents would like. In some areas, the service is overstretched and children may only receive sporadic visits. Many parent support groups run their own speech and language sessions with an independent therapist.

Speech and language therapy

Example of the difficulties in obtaining speech and language therapy from the DSA helpline

Ella is 4 and has just started mainstream primary school and James is 12 in mainstream secondary in different parts of England. Both of their families had to go to an educational tribunal to get individual speech and language sessions as legally enforceable provision. However, in both cases, the local speech and language therapy service now wants to reduce this to termly monitoring with no individual sessions, so the families are looking at further tribunal appeals, which will be costly in terms of effort, expense and strain on the parents.

Health Issues at School

Some children with Down syndrome may have additional health issues that affect their education. Coordinating health support in mainstream schools can be difficult and families often find themselves having to liaise with different professionals. Children with Down syndrome who have additional health needs should have a health care plan drawn up in collaboration with parents, the school and relevant health professionals. Often the school

nursing service can help coordinate this. Teachers in England are not obliged to administer medicines, so it should be written into the plan who will do this—this could be an appropriately trained TA. Schools may be anxious and overcautious where health needs are concerned, so it would helpful for them to be given specific medical information relevant to the particular child.

Where children are likely to miss a lot of school for health reasons, the school should be planning in advance for this by having work available to send home and thinking about how the child can keep in touch with classmates. For long-term absences, it may be possible to arrange for some home tuition.

Behaviour

Generally, positive behaviour approaches with lots of positive reinforcement when a child behaves well are most effective in supporting good behaviour. When challenges do arise it is important to remember that most behaviour problems can be addressed by parents and school working together, calling in outside help if necessary.

Behaviour problems as such are not an intrinsic part of Down syndrome. Difficult behaviour can occur for the following reasons:

- Immaturity—a child is showing behaviour that is typical of a younger child.
- Communication skills—maybe the child is not able to tell another child to go away or that he or she wants to join in or may not understand what is required of them.
- Frustration because of increased demands at school.

It is helpful if everyone works together to find out what is behind a certain behaviour. The school should carry out an ABC (antecedents, behaviour, consequences) analysis; outside professionals such as an educational psychologist or a behaviour support teacher may be able to help with this. The school can then draw up a behaviour plan with agreed strategies. These might include social stories or visual reminders to understand how to behave. Generally, positive behaviour approaches with lots of positive reinforcement when the child behaves well are most effective.

Getting inclusion right

Example from the DSA helpline

Sophie is 8 and goes to her local mainstream primary school with her brother and sister. Her mother rang the DSA as she was constantly being rung by the school complaining about Sophie's behaviour. She was a bit baffled about this as Sophie is well behaved at home and fits in well with the demands of family life. It turned out that Sophie was being taken out of her class every morning and being taught with children 3 years younger than her. When she returned to the class in the afternoon, she spent her time sitting on a separate table with a Teaching Assistant and had no interaction with her classmates. Sophie lost the friends that she had made in previous years and became very isolated. As she is a sociable child, she became frustrated and showed this by her behaviour in school.

Family and community life

During the school years children with Down syndrome will, like other children, be moving from doing most things with their family to becoming more independent. They will be doing the same kind of activities as their brothers and sisters, sports, arts, dance, scouts … Families want their children to be fully included in community life but this may need a lot of parental support. They need information about outside sources of support. It is a good idea to get the child's and family's needs assessed by the local social services or children's services department. This may open the doors to additional help such as a carer to take the child out to activities or give parents a break. This may be arranged by a 'direct payment' so that families can employ someone of their choice. As children grow, it is important to encourage independence by having someone else apart from Mum or Dad involved in some activities.

If social services know about the child when he or she is still young, there is less likely to be difficulty getting support once the young person approaches adulthood.

Moving on to secondary school

Where children are moving on to secondary school at age 11, parents should start planning ahead when their child is about 9. Many children do progress to mainstream secondary and are able to sit exams and obtain qualifications. Some parents may consider a special school if they feel that their child would not manage in the large and busy environment of a mainstream school. It is important to remember at this stage that children with Down syndrome cover a whole spectrum of abilities and needs, so it is vital to keep an open mind and focus on the individual child.

Some additional questions to think about at secondary level are as follows:

- How big is the school site? How secure? How often do pupils have to move around?
- How are children with special educational needs supported? Is this by TAs in the classroom or are children taken out to a separate learning support unit?
- How does the school support friendships and social interaction?
- What happens at break and lunchtimes? Are there clubs at lunchtime or after school?
- How do they differentiate the curriculum, especially at the age when most children are doing exam courses?
- How will the child get to school? Is transport available?

Adolescent years and transition

Mood swings, pushing the boundaries, tiredness, confusion, crushes, first loves, introspection and spending ages in the bathroom. These may occur a little later and last longer in some people but a teenager with Down syndrome will essentially be like any other teenager. Sexuality, a desire for greater independence, a need for more personal space, encouraging good personal hygiene, explaining and facilitating relationships and fostering self-esteem are some of the issues that need to be considered. Parents worry about the future and what will happen to their child; teenagers begin to develop a sense of self and independence and

have to come to terms with their condition. The changes brought by adolescence will have a greater impact for some families than others in the difficulties they present and their intensity and timing.

What does the future hold?

As their children travel through adolescence, all parents have concerns about what the future holds. For parents of children with Down syndrome, their fears are more pronounced as they must increasingly depend upon the support of health, education and social care professionals in planning for the future of their children. Families who call the DSA helpline ask for a map to navigate the labyrinthine system called 'Transition' (the period between 14 and 25 when people move into adulthood). *Transition* is a word most first come across at the year 9 review when they are asked to begin planning for their child's adult life. Representatives from health and social care are supposed to attend along with their education colleagues; however, this frequently does not happen. The quality of such reviews is variable and the advice of one father based on his experiences is to

> *... find out as much information as you can. Especially speak to parents with an older son or daughter who is already in receipt of adult 'services'. Find out what leisure and employment opportunities are available and find out about different housing options. Start to put together a person-centred plan for your son or daughter yourself. No-one else understands them and their needs and aspirations like you do. It's a document that you can put together during the teenage years, and tweak and modify it as you go.*

The onset of adolescence raises a number of questions for parents:

- Can they go to college?
- Will they be able to work?
- Where will they live?
- Who will look after them when we are not there?
- Will they have relationships and maybe get married?
- Can they have children?

The answers will be determined by a vast number of variables:

- The degree of support necessary for an individual to be independent
- Is there a suitable college or work placement?
- Are social care and health services supportive in planning for the future?
- What are the local housing options like?
- What leisure activities are available in the community?

Many young people with Down syndrome have similar questions as they grow into adulthood and become more aware of themselves, their abilities and the abilities of those around them. Those attending mainstream school see their peers achieve a level of

freedom and independence in their lives which is denied them and this can cause friction at home.

Churchill School has taken on board the broader view of secondary schooling and asked the question, 'What are the long term goals for Tom?' If Tom is to become a successful adult, happy about who he is and optimistic about his future, then he needs to become as independent as possible, and it is understood that it will be the years spent at Churchill that will help him get there.

Churchill staff have viewed Tom as an individual with needs like any other student and have developed an insightful means of empowering him and allowing him the autonomy that will serve him well in future life. They have not stunted his development by erecting a safety boundary around him to protect him. Tom is a shining example of the successful transfer of a student with Down syndrome to a large mainstream secondary school. His placement is supported by a strong partnership with his family and the local Down syndrome group.

Most young people with Down syndrome become increasingly aware during this time of the differences between themselves and their mainstream peers who they see achieve greater independence. As with all children, positive experiences during this time will strengthen their ability to cope in adulthood. The case of Tom shows how the impact of collaborative working, timely planning and the ability to be flexible can support a young person to gain skills that will support him or her in adult life.

Getting the assessment right

Perhaps the most important question of all for a teenager and his or her family experiencing the 'Transition Process' is the Adult Care Assessment which provides the gateway to support from adult social care. This assessment looks at whether a person needs support, what that support should be and how it is to be provided. It should cover all areas where a person needs help—for example, daily living, health, work and/or education and leisure. People with Down's syndrome can often be underestimated in their abilities because of their poor communication skills but some young people who appear articulate can have their abilities overestimated because of their language skills. In either case, a poor assessment of needs can result if there is not sufficient evidence gathering and time set aside to plan collaboratively. Calls to the DSA helpline highlight poor practice in this area. Parents are often ill-informed and unprepared to support their child in getting a robust assessment of their needs, and social workers fail to gather sufficient information to support the assessment or fail to carry it out in a timely fashion. As a result, young people leave school at 16 or 19 years of age and say goodbye to a structured day and a network of friends and after-school activities and step into the unknown. Parents have to support their child's social life and depend upon there being suitable local activities available.

A lot of Jack's activities in the evenings and weekends are geared to making him as independent as possible, for example, going to the dry ski slope every week means

that he keeps his skills ready for the next skiing holiday. Jack also attends a fantastic youth club, run by dedicated volunteers for typically developing teenagers, which is split into age groups. Here he can dance, play pool and go on trips. Jack also plays football and wants to have drumming lessons. He was doing regular gymnastics but is just starting a new football club run at a local community college for students with additional needs.

It is vital that all the people involved in a young person's life in both a caring and professional capacity work together to support him or her in planning the future. Agencies have a duty to collaborate. Parents speak of this time as *stepping off the edge of a cliff* or *staring into a black hole* and have negative experiences of the information and support provided.

Mrs. S' son has complex needs requiring a high level of support from education, health and social care. He had been placed in an independent specialist provision for 11 years but this was coming to an end. The establishment was able to support him post 19 but funding needed to be arranged for the following September. Mrs S was concerned that a local mainstream college had stated it could meet her son's needs despite not having seen the young man for over a year. The Learning Difficulty Assessment carried out by a representative of the authority stated that he would be at risk in a mainstream college. Mrs. S had waited patiently for 3 months, following the assessment in February to hear about a decision regarding her son's future. She approached the DSA for help in a state of anxiety in May, requiring support in discovering what her local authority had in mind for her son. She was not aware of the transition process or the individual responsibilities of the agencies involved in her son's care. She did not feel meaningfully involved in the decision making process and had no one she could trust to guide her through the current situation.

The situation causes stress and frustration for families and can impact upon their mental health and financial status. Some parents give up work to care for their child as they are not aware of their rights as carers and those of their adult child. Information is available from charities like the DSA and DS Scotland in addition to that which local authorities must provide by law on their website. The problem can often be knowing the right questions to ask. Parents need to be tenacious.

What are the barriers?

In 2011, National Foundation for Educational Research (NFER)[1] carried out a study into the experiences of young people with special educational needs/intellectual disabilities and disabilities: research into planning for adult life and services. The findings were not a surprise to people with Down syndrome and their families and indicated the following:

- Transition planning usually begins too late and is too focussed on short-term goals.

- There are low expectations of what people with an intellectual disability can achieve, which can limit their options.
- There is a focus on education provision rather than planning for independent living beyond college.
- There is a lack of suitable opportunities for young people with Down syndrome in accessing meaningful college courses, community activities and work.
- There is concern about the lack of capacity in services, in terms of levels of staffing, staff expertise and workload.

The solution seems simple:

- Involve young people and families in planning the future.
- Ensure agencies work collaboratively to support families.
- Improve the assessment process for adult care support so that young people are able to live, socialize and be actively involved in their community.
- Provide adequate staff and training levels.
- Provide meaningful college courses to prepare people for adult life with appropriate levels of support.
- Provide employment opportunities for those who want to work.

Achieving them is a much greater challenge as success will be in part determined by the pattern of government spending.

What are the possibilities?

As people come to the DSA, for the most part, when they need help and support, it is easy to paint a negative picture, but there are also positive stories from people with Down syndrome, their families and employers about what happens when things go well. It is very important to remember that teenagers with Down syndrome have hopes and dreams like anyone else and some are able to realize them. The following are some of the success stories.

Nathan

Nathan Walker has ambitions—he has a girlfriend who he likes to take out, he hopes to live in his own place, he looks forward to holidays abroad and he wants a job so that he can afford to pay for all of this.

Andrew

Andrew is 16 and is always on the go—he flips on the trampoline, plays cricket, football and does the most amazingly perfect cartwheels—he is very flexible—but the thing he enjoys most is dancing. He dances before he goes to school, at school and most of the time at home—in fact—he hardly stops dancing—our own little Billy Elliot. Andrew says he wants to be famous too because dancing makes him feel happy and great.

Path and Peter

Path and Peter, both born with Down syndrome, have been in a relationship for more than 20 years. Fifty-seven-year-old Path and sixty-six-year-old Peter live with three other people with special needs, in a house managed by a few caregivers. Ever optimistic Peter is the joker in the relationship; Path is more calm and measured. The pair enjoy strolls in their garden and the company of each other.

Prem

Eighteen-year-old Prem works for 6 hours a day for 2 days a week at Brown's Hairdressing Salon. He needs more support than some others from the DSA's WorkFit programme, but this reality has not stopped him thriving in his role or from becoming a valued member of the workforce. He feels included and understands the routines necessary for the world of work.

Sara

Sara is a young woman who has Down syndrome. Sara has held a number of volunteering positions including an administrative role at the Down's Syndrome Association's Wales Office, as a community councillor and on an oversees visit to Lesotho with Mencap. Sara now works for Mencap in Wales as a 'Partner in Politics Officer' and has established herself as an actress who has recently toured with Hi Jinx Theatre Company, Wales.

Andrew

Tyre fitter Andrew is a first rate employee. He started here not long after I was put in charge of staff training and to begin with I was Andrew's mentor. He was quick to learn and has incredible attention to detail. He is so fastidious and that's important in a workshop environment. Many of the other guys here could learn a thing or two from Andrew. We were first approached by a local intellectual disability training and employment organization called Gabalfa Community Workshop (now Vision 21). Andrew had gained a lot of practical skills by being involved with their training projects and the next step for him was some work experience. We were happy to offer that and we've never looked back.

At first we had regular input from the employment agency who assigned Andrew a 'job coach', but we soon realized that Andrew was coping well and that hands-on support phased-out, with us taking over this responsibility. When discussions took place about whether we could offer Andrew a paid job, we did so without hesitation—he is a valued employee.

Guy and Esme

Guy and Esme were married in 2010. They live independently with Guy's best friend whom he has known since early childhood. They rent a small house and share duties such as shopping, cooking and housekeeping. A small team of carers go in (one at a time) for approximately an hour each morning, 2 hours each evening and 3 hours

for each adult once a week for their personal care and house duties. They met at Foxes Academy College where they completed a 3 year course in catering and life skills. This prepared them both for their independent living skills and their personal development, so that when they returned home, they immediately moved into their own home with their friend who also went to college at Foxes.

Puberty and some sexual health issues

'Sexual health is a state of physical, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence' (World Health Organization definition).

The timing and sequence of puberty is broadly similar to that of all adolescents. People with Down syndrome experience the same feelings of human sexuality as the general population. Sexuality influences an individual's self-worth, interpersonal relationships and social experiences. People with Down syndrome have sexual feelings and the need for intimacy. These issues require sensitive handling and good practical advice and consideration of health issues.

How will my child and I cope with managing her periods?

The majority of women with Down syndrome do not require help with menstrual hygiene, although at times 20% need help changing pads and a minority may consider medical treatment to alter their menstrual pattern. As with all women, many women with Down syndrome experience some kind of menstrual disorder—heavy, painful, scanty, non-existent or irregular menstrual flow—at some point in their lives. In Down syndrome, it usually takes 6–18 months to establish a regular menstrual cycle. There are conflicting reports but the age of the menarche in Down syndrome is similar to that in the general population and similarly seems to be falling. Girls start menstruating towards the end of puberty, though occasionally it can be the first sign of puberty. The average duration of menstrual flow is 4 days (3–6 d) occurring every 25–30 days.

Menorrhagia (prolonged/excessive periods) and metrorrhagia (frequent/irregular periods) are the most common complaints in women with Down syndrome. Any menstrual disturbance should be fully investigated, bearing in mind that thyroid dysfunction can cause menstrual irregularities. Once treatable medical disorders have been excluded, treatment options can be discussed. These include mefenamic acid or tranexamic acid for dysmenorrhoea; and progesterone and oestrogen hormones, for example, depo-provera injection, progesterone-only pill, combined oral contraceptive pill and implant for irregular or heavy periods. Caution is necessary in women with a medical history of congenital heart disease, venous thromboembolism, migraine with aura, obesity and immobility when using oestrogen-containing medication.

Kirsty was 12 years old when she started her periods; she was anxious and unable to attend school during her next three periods. They were heavy, painful and irregular. She is independent for toileting when she is not menstruating. She has regular support at home and school to help establish a routine and independence for managing her periods. After 12 months, her periods are now regular and less painful.

She is confident and is able to manage herself at period times. However, her periods are heavy for the first 2 days and restrict her physical activity. Kirsty's parents are now considering whether using hormonal treatment to reduce or stop her menstrual flow would be in her best interest.

Do children and young people with Down syndrome need the human papilloma virus vaccination?

The risk of cervical cancer is very low if a woman has never been sexually active. So when deciding whether to vaccinate against the Human Papilloma Virus (HPV), it is important to remember that it is difficult to predict future sexual behaviour. Cervical cancer may also be diagnosed late when symptoms are not reported or cervical smear tests are not tolerated well. The HPV vaccine has been offered to all 12–13-year-olds since 2008 in the UK. In the UK, it is given by the school nursing service, three injections, preferably over a 6-month period. It is well tolerated. Common side effects are mild, such as redness at the injection site and headaches. HPV vaccines protect against a number of HPV types, offering protection against genital warts, premalignant genital lesions and cervical cancer (see Resources for UK government guidance).

Claire is 13 years old; she brings home a consent form for the HPV vaccine from school. Her mother is unsure whether it is in her best interest to have the vaccine. Claire expressed a wish that she would like to have children in the future. On further discussion with Claire, her parents, school nurse and paediatrician, it was felt that it would be beneficial for Claire to have the HPV vaccine as it is difficult to predict future sexual behaviour.

Is contraception needed?

There have been many pregnancies in women with Down syndrome. Most women with Down syndrome ovulate and approximately 50–70% are fertile. Men with Down syndrome have lower fertility than the general population; however, there have been at least two reported proven cases of men with Down syndrome becoming fathers (Pradhan et al. 2006). Women with Down syndrome who become pregnant have a much higher risk of miscarriage, and having a child with a chromosomal abnormality. There is an increased risk of low birthweight, congenital abnormalities in the infant and pulmonary hypertension in the mother (see Chapter 8).

Young people and adults with Down syndrome have a right to express emotions and sexuality and develop relationships as an important part of a full and equal life based on a right to independence, control and life choices.

People with Down syndrome have a right to

- fulfil personal and sexual relationships;
- marry or cohabit;
- make an informed choice about whether or not to have children;

- take risks and make mistakes in personal relationships;
- privacy and freedom from exploitation;
- receive sex education, including counselling on personal relationships, and the social rules of sexuality, sex and sexuality, contraceptive advice and sexual health support services which should be taught at a developmentally appropriate level. These lessons are compulsory in England from age 11 onwards.

Young people and adults with Down syndrome may wish to form relationships and may be able to manage all aspects of their relationship but some will need extra support when considering contraception and pregnancy.

Women with Down syndrome who are sexually active or planning to become sexually active need to be supported in considering and choosing appropriate contraception. All hormonal and barrier methods of contraception should be considered ensuring that the most appropriate choice is made, taking into account the medical history and level of ability. A medical history and examination needs to rule out any contraindications to the use of oestrogen-containing contraceptives (see above). Progesterone-only methods, for example, progesterone-only pill, depo-provera injection or a progesterone implant may be preferable in the presence of oestrogen contraindications. Long-acting reversible contraceptive (LARC) methods, for example, implant, depo injection or an intra-uterine device, should be considered to reduce the failure rate if there are concerns about compliance issues.

Barrier methods such as the condom and diaphragm can be very effective at preventing pregnancy but need much practice to use safely. These are probably not practical for those with an intellectual disability who lack dexterity.

Helen is 19 years old and lives with her mother and sister. Helen has epilepsy and takes carbamazepine. Helen is becoming increasingly independent and would like to have children in the future. Her partner attends the same College course. Her periods are very heavy and she needs support during menstruation, but otherwise toilets independently. Helen meets regularly with a doctor and nurse at her local Contraception and Sexual Health Clinic. It is clear that Helen has capacity to consent to treatment; she receives appropriate sexual health advice and decides to start on the progesterone depo injection. Helen is pleased with the subsequent reduction in her periods and is also aware of its contraceptive effect should she become sexually active in the future.

Male sexual health

There is no doubt that men with Down syndrome have the same array of sexual feelings as any man. However, impairment in social skills both in them and women in their peer group along with limited social opportunity usually restricts the number of sexual encounters. Sexually transmitted disease is, therefore, very rare. Personal hygiene, especially cleaning under the foreskin, may require some prompting. Occasionally, and usually in those with more severe social impairment, masturbation in an inappropriate setting requires behavioural management intervention. We have found no reports of erectile dysfunction. They

must exist and would need standard management adapted to the personality and ability of the affected person. Yearly testicular examination should be encouraged as men with Down syndrome are at higher risk of testicular cancers (see Chapter 14).

Adult life with Down syndrome

Introduction

Adults with Down syndrome are likely to have the same aims and aspirations as others: to be happy and flourishing members of their family and their local community. This is a realistic goal but is generally achieved only with some level of support from parents and professionals. Increasingly, people with Down syndrome are living in their own homes with support, finding employment and getting married.

However, for some young people, once they reach the age of 25, much of the support they have enjoyed through their school life and at college is reduced or disappears completely; families are left having to work hard to find the right help to continue appropriate inclusion within the local community.

This section aims to provide an overview of the variety of situations that people with Down syndrome encounter in their adult life.

A place to live

Many adults with Down syndrome aspire to leave the parental home and set up in a place of their own. The UK government policy endorses this aspiration and allows for the provision of support to enable people to live independent lives.

However, 60% of adults with Down syndrome at the age of 30 still live at home with their parents/families (Carr 2008).

Kirsty lives at home with her mum and dad. She is in her mid-thirties and has a very active social life. She has two brothers, and a sister who lives in Canada. Kirsty has been to see her sister several times with her mum and on the last visit took advantage of assisted flights and visited her sister by herself. She was delighted (and a little bit scared) that she was able to do this by herself. Kirsty has no support from the local authority currently, as the family supports Kirsty in all her needs. Her parents worry about what will happen to Kirsty when they are no longer around to care for her, and other than staying at her sister's house, Kirsty has little experience of being away from home.

Most people with Down syndrome can live independently from their parents when adequately supported.

Jane lived at home with her parents until she was 19, and then attended a residential college to study on a catering course. At the end of her course, she returned to her local town and worked with her parents and the local authority to find a place to live. There were several opportunities available to Jane, but with advice from her family, she decided to rent a flat from a housing association. She now lives with a

friend who also has a learning disability. Jane uses direct payments to buy the 24 hours of support she needs each week to help with some of the tasks she finds difficult. Jane's parents live close by and provide support in other areas. Jane is helped to manage her money, is helped to look after her health and her home and has support to maintain her employment. Jane enjoys a similar lifestyle as her brothers do, going to the cinema and bowling, out for meals when her budget allows and meeting up with her family for Sunday lunch. Jane belongs to an amateur dramatics society and performs in a variety of locations. She also loves gardening.

Other people have particular needs that are currently not being met under the social model of care.

At 23 only recently received any support having lived in county for almost 15 years. Very few available adult services—**Parent**

This includes a range of medical needs as well as support for specific cognitive difficulties. Indeed, the recognition of medical need and specific difficulties is essential to an optimum level of support. Some people with Down syndrome get good levels of support, and others have to fight hard to get any support at all. Families often need help to challenge various agencies to provide adequate support.

Good health

It has been known for some time that adults with Down syndrome experience poorer health than the general population and are less likely than others to access regular health checks or routine screening.

As well as being predisposed to certain medical conditions such as cardiac disease, thyroid disorders, hearing impairment, visual problems and coeliac disease, people with Down syndrome may be more prone to depression, and dementia can occur earlier than in the general population (see Chapter 18 on neuropsychiatry).

In England and Wales, annual health checks have been introduced for people with intellectual disabilities to address the inequalities in health care, but uptake has been slow. People with Down syndrome now have access to a user-held health book to encourage general practitioners (GPs) to pay attention to the specific health problems that occur more commonly in people with Down syndrome. For more detail you can visit the Royal College of General Practitioner's website and download the document 'Annual Health Checks for People with a Learning Disability'. The UK Down's Syndrome Association website offers more detail on the DSA Health book for adults and advice on adult health check content (see Appendix 1 at the end of the book for links).

It's good to keep a record of your health and start to improve on any issues. It helps me remember, having it written down. My key worker and parents can share the info. I can keep an eye on my weight. I understand better which medicines help me with different things—**Matthew**

This is a first step towards people taking care of their own health, but carers still need to provide significant support in this area. Where appropriate support is not available, significant issues can arise. Guidance for care staff on specific health issues is very important, and health professionals can help to inform social care assessments to ensure adequate support is provided to maintain health and well-being.

Mary attended mainstream school, attaining several Certificates of Achievement. She was a confident, happy, well-adjusted and sociable outgoing young woman. At the age of 23, Mary was funded by her local authority to live in supported accommodation. Two years later, after consistently being left to make uninformed choices about her diet, clothing, health care, medication and hygiene, her parents observed a drastic deterioration in her mental, emotional and physical health. Feeling out of control, she took refuge in routine to the point where normal day-to-day activity became severely compromised. She suffered constipation, overflow and incontinence of urine due to her poor diet and lack of compliance regarding medication for slow gut motility. She had poor hygiene and was continually feeling anxious about her situation. Mary finally received psychological assessment followed by some psychology support, leading to some improvement in her emotional state as well as her toileting issues.

Menopause or other treatable health conditions

Women with Down syndrome on average reach the menopause earlier than the general population at the median age of 46 years. Hypothyroidism does not influence this age. Hot flushes, mood swings and night sweats are commonly experienced but symptoms can vary. The menopause should not be blamed for a change in function or new symptoms in a woman in this age group. A medical assessment is always important to rule out other medical causes such as hypothyroidism or depression (Seltzer et al. 2001, Schupf et al. 2003).

Joy is a 44-year-old woman who has lived in supported housing since her mum died when she was 30. She has developed irregular periods, become socially withdrawn and her hygiene levels have deteriorated; she has been gaining weight and is reluctant to eat. Her sister wonders if she is going through the menopause. At her annual GP assessment, it was clear that she needed further investigation as hypothyroidism could explain her symptoms. A blood test later confirmed hypothyroidism and her symptoms improved with treatment with levo-thyroxine.

Choice and autonomy

Making choices is something that we all do every day; some choices appear minor but are important, for example choosing the colour of the paint in your bedroom, whilst others are fairly major, for example, moving house or getting married, but they all help us to form our identity and contribute to our feelings of independence and self-esteem.

It is important to recognize that people with Down syndrome have the same rights as other adults—they should have the autonomy to do what they can and should expect to receive help and support when this is needed.

People with Down syndrome can often perform certain tasks very well, for example cleaning the home or preparing food. However, some people may make poor decisions, particularly where these require motivation or organizational skills. Getting it wrong with sleeping, eating and leisure activities can be harmful to health, well-being and self-esteem, with many families reporting poor self-management of diet and physical activity.

Sarah lives with two other people with learning disabilities in a house on the outskirts of town, with support. She is overweight and spends no time doing physical activity, because the carers do not have enough time allocated to go with her for swimming sessions, which have been recommended by her GP. Her carers will agree readily to providing a poor diet, based on the premise that Sarah asks for burger and chips for her evening meal most days. However, Sarah's friend will eat with her once a fortnight, and on those evenings, Sarah is helped to choose between two alternatives (neither of which is burger and chips)—and Sarah has no difficulty in finding a healthier option. She can explain which foods are healthy and which are not, but this is never discussed with her care team. She is also happy to be involved in the preparation of food, but her care team tend to do this for her.

Where Sarah is supported to make good decisions which are appropriate to her skills and abilities, she is able to do this. Visual recipes and cooking with others can reinforce good eating habits, as well as taking an active role in menu planning and shopping for food.

A different problem that people with Down syndrome frequently have to face is others making decisions on their behalf, when this is not only unnecessary, but completely inappropriate.

Sam and Jo have been in a relationship for some years. They had decided to get married and were busy making the arrangements for their wedding. They had seen the registrar and the vicar of the local church and a date had been set. Out of the blue, Jo's family received a visit from the local authority, advising the family that the wedding could not take place as Jo did not have capacity to consent to the marriage. They insisted that Jo had an appointment with a psychologist to be assessed for her capacity to make this decision. The psychologist refused as she did not consider the local authority had grounds to insist on this. Social services eventually dropped the issue, and the couple went ahead with the wedding.

Choice and autonomy should be encouraged, but it is important to ensure people are not put under undue stress, with too many options too soon; this can lead to feelings of anxiety. However, people sometimes have to take risks in life to achieve their aspirations.

My daughter was depressed and wanted to leave home as there was nothing here in the outskirts of the town. She wanted a chance to participate in life. 'Life's not worth living for disabled people'. 'It's boring living opposite a field'. We have irregular bus and taxi services and the walk to town is 1.5 miles. The Social Worker was very apprehensive about our daughter's move and even got the community Nurse involved to state reservations when a placement was offered at the Housing Scheme (neither had visited). Our daughter did us all proud when she read from a list she had written, 'My reasons for wanting to move'. This clinched the decision and all were in agreement for the move. A year on, she is a different young woman. She has got her bubble back, is more confident, happy and has an aura of self-importance. Eventually, she is her own person. I am so relieved and happy for her—**Parent**

Leisure and work

Some people with Down syndrome may find it difficult to attend social or recreational activities if they are responsible for organizing them, leading to isolation and a risk of depression. People should be supported to maintain their current friendships as well as making new friends.

People with Down syndrome need opportunities to participate in the life of their community through personal hobbies and interests, community events and employment, as this will boost their self-esteem and help develop and improve social skills. Interaction with others through a range of activities can provide the social connection necessary for well-being.

After attending college, many young people with Down syndrome find it difficult to find appropriate activities to stay occupied during the day. Sometimes, they will attend specific activities aimed at people with intellectual disabilities, but many would like to work. There are a number of schemes available that help people with disabilities find employment, sometimes voluntary, sometimes paid.

Will has been working as a volunteer ranger and horticulturist at Hardwick Hall National Trust since October 2012. He has developed within the role and the staff know that if needed William can be left to get on with a task once the requirements of that task are established. Some people might have preconceptions, but they are unfounded as far as I am concerned… Will is one the team—**Head Ranger Steve**

However, people with Down syndrome are often not well supported by these programmes, and in the UK the DSA developed a specific project—WorkFit. This has improved access to mainstream employment and other meaningful activities for people with Down syndrome.

Jenny is 24 years old, who in her spare time is a keen actor, having appeared in films alongside famous actors like John Hurt and Elijah Wood. She was also in the

opening and closing ceremonies of the Paralympics. Via the WorkFit program she has found a paid work placement with a specialist insurance broker in Billericay Essex, where she has been working for the last 12 months.

Jenny's duties include managing the post, including updating the post-log, franking, shredding and sending out quotes. Jenny is a productive and valued member of the team. She is closely supported by her supervisor, who has made some adaptations to work practices to ensure success. For Jenny, the placement has allowed her to achieve her goals; she has more self-confidence and this has opened up more opportunities for her. Being paid for her work not only makes her feel great but allowed her to 'invest' in a holiday later. Jenny is thoroughly enjoying the job and the people; the benefits are seen at home too where Jenny is now motivated to get up in the morning; she happily tells her family, friends and particularly her boyfriend about the job and encourages her friends to sign up for WorkFit.

Jenny is not a stranger to work and has experienced a variety of jobs. Prior to her current role, Jenny had attended a training centre run by the Salvation Army where she worked as a waitress in their tea rooms and also learnt some office skills. Jenny had previously undertaken voluntary front of house work with a theatre for 3 years, which she loved but which unfortunately was unable to survive the economic downturn. Whilst Jenny had clearly been active and had experience of a work environment, she had not had a 'proper' regular paid job.

Travel to work training can be accessed on an individual basis, developing independent travel and problem-solving skills, as well as providing general support for those who need it.

Joe can catch a bus from his home to the railway station, get the train and then a tube to work; he can also return home. However, as yet he is unable to catch a bus to an adjoining town, as he does not know the route and is unable to transfer the skills he has learnt from the one journey to another. Joe does know how to contact a member of his support team by mobile under any circumstances if his phone is switched on—he has not learnt, however, to keep his phone switched on, making it problematic when someone needs to contact him. Joe is working with his support team to develop his independent travel training skills.

The common theme here is working out how to create opportunity and encouragement for people with Down syndrome so that they can fulfil their aspirations, at least the realistic ones). Even after the age of 25 when many support networks melt away, the opportunity and encouragement can be achieved through good liaison between parents, care staff, church groups and other community support networks, college (there are many suitable courses for non-disabled), the DSA, social services and so on. The key ingredients for success are energy, time, persistence and creativity.

Down syndrome and dementia

The link between Down syndrome and dementia has been recognized for many years; however, it is still very distressing for family and carers when a person they know is suspected of having or has dementia. The real-life situations in this section will help to inform health care professionals of some of the attendant feelings experienced by affected people with Down syndrome and the relatives who offer them care. They will inform practice and how best to help.

In the world of intellectual disability, the emphasis is on supporting people to be as self-sufficient as they possibly can be. When dementia occurs, the focus of care changes so that the individual can be reassured and kept as safe and calm as possible, whilst receiving increasing amounts of physical and nursing care as the condition progresses. This change can be difficult for all concerned and it is important that relatives and staff understand how dementia affects the individual so that they can offer the best support. The diagnosis of dementia is the starting point; accepting the changes that will happen, beginning to collect stories and information about the individual to share later on, thinking about life experiences and noting things that mattered to them will all help in the later stages. Celebrating the person as they are at that point is key to creating the optimal environment.

How do we get a diagnosis?

My brother is 51 and over the last few months he has been slowing down and losing skills—the community nurse has mentioned dementia and we need to know what will happen next.

The starting point is a psychological assessment. The first point of contact for most families is their GP, particularly if a relative does not have contact with the local Community Learning Disability Team (CLDT). The GP will make the referral to the psychologist, although in many areas families can self-refer. The assessment will define how well the individual manages in daily life and should involve someone who knows the person really well and who can discuss what changes have been observed.

In some areas, people have a baseline assessment of abilities done by the CLDT and this will be used as a benchmark to help identify any changes. It is recommended that all people with Down syndrome aged over 30 have such an assessment. It is worth family and professionals checking whether one has already been done.

My sister had a query of dementia but recently when she was in hospital, the nurse said she thought it was all down to the menopause.

Our brother was being assessed for dementia, they mentioned depression and that made sense since it's not long since we lost our mum.

There are many other health issues that can present the same signs and symptoms initially as dementia and it is important that these are considered and eliminated rather

than jumping to the wrong conclusion. Women going through the menopause may experience symptoms which could be mistaken for dementia such as forgetfulness and lethargy. Depression causes people to become sad and withdrawn, less interested in the things they used to enjoy and altered sleep patterns—all of which could be mistaken for dementia.

It is really important that the GP considers these alternative diagnoses so that appropriate treatment is given (see Chapter 18).

Does the person with Down syndrome know that they have dementia?

My brother is still living at home with our mum; he is getting very reluctant to do things and is happy just to sit around all day. It's not like him; he used to be very sociable and outgoing.

Although people with Down syndrome may not understand the word *dementia* or its implications for their life, they are usually aware that something is happening to them. This can make the world feel scary and unsafe and the individual may choose to stay in the place where they feel most secure.

It is important to acknowledge that something is happening and to provide reassurance them that it is okay; that parents and carers will be there for them. You do not have to mention dementia, which could be meaningless anyway, but perhaps saying something like, 'it's your memory that's changing, it happens to lots of people' can help them feel better and less unsure. Remember that even people with Down syndrome who have lived with someone with dementia may not recognize that the same thing is happening to them.

With gentle reassurance and by making the world feel as safe as possible, the individual can be supported and encouraged to continue to participate in the activities and interests they have always enjoyed.

Getting the right support

My brother lives with us and has just been diagnosed with dementia, what can we do to help him and where can we go for support?

It is important that when a person with Down syndrome is diagnosed with dementia, as far as possible, he or she maintains the same her routine, daily activities and social lives, for as long as possible. However, adaptations to the environment and the individual's care package will have to be made as the dementia progresses.

Social services should be informed of the recent diagnosis and altering circumstances. A new community care reassessment should be requested to identify changing needs and additional support within the home. This should include long-term planning so that changes can be accommodated later on. There should be continuing contact with the CLDT psychologists, nurses, speech and language therapists, physiotherapists and occupational therapists who will all have important roles to play as the dementia progresses.

The onset of epilepsy

My sister has started having seizures, they are horrible to watch and I didn't know that they are very common with dementia, I am quite angry that none of the professionals we see told me about this possibility.

Sadly, the majority of people with Down syndrome who have dementia also develop epilepsy after a couple of years. This should be seen as a treatable consequence of the disease. It is important that appropriate antiepileptic medication is prescribed to reduce and control the seizures as much as possible. The hospital epilepsy clinic, specialist epilepsy nurse, GP or intellectual disability nurse can all be useful sources of advice on medication and monitoring.

Creating a supportive environment

My son isn't walking around like he used to, he sometimes totally refuses to go outside.

We are really concerned about his safety on the stairs, he has started turning the landing light off and coming down the stairs in the pitch black.

One of the first things that happens with dementia is that people lose their 3D vision, which makes getting around very difficult, especially coming downstairs, negotiating steps and moving from one type of floor covering to another. Typically, the person will toe-tap the edge of the stair, kerb or carpet before they take a step.

In the home, floor coverings should be kept as similar as possible. Stairs can be highlighted using brightly coloured strips at their edges to help the individual know where the step ends.

Colour is very important—dark colours (black, navy, dark brown, etc.) can look like holes or something to be stepped over, bright colours (red, yellow, orange) can help the person to identify objects more easily. Red toilet seats can help the person identify and use the toilet.

My daughter used to like sitting with us at the dining table but won't do that at the moment, it's a shame as she isn't eating properly anymore.

Having clearly identified areas can help the person with dementia to understand what is happening. Sitting at a dining table is a great clue that food is about to arrive. It is also a social event. A check should be made whether the person can sit on a chair with his feet on the floor—if he can't, it makes him feel very unsteady as he may rock to and fro whilst trying to eat. Placing a footstool underfoot is a simple, but effective, way of helping someone to remain stable.

I hadn't thought about why she never left the living room, I did think it was odd that she kept talking about the hammer stuck in the wall.

Doors should be visible; white doors next to pale cream or white walls can disguise exits and mean that people remain in one room all day because they cannot see the way out. The hammer in the wall was actually the door handle.

What can I do to keep him to keep calm when it's starting to go dark, he gets very upset when the light starts to fade?

Many people with dementia struggle with the change in light as afternoon becomes night and it can affect their behaviour during the evening. A good idea is to turn on lamps whilst it is still light and close the curtains before it goes dark outside. This will reduce reflections in the window and any agitation caused because there is a 'man in the garden'.

[We had] *5 burnt out electric kettles before it dawned on us that we needed to get one that goes on the gas cooker! Sometimes, it's the simple things that make the most difference.*

As the person begins to roll back in time, it is important to have objects and mementoes around, which will help them to feel 'at home'. Photographs of family members, ornaments from years gone by, family heirlooms like clocks and pieces of furniture can be very comforting when someone is losing the ability to recognize more modern items. Making the environment feel homely and safe can have a massive impact on the individual.

Changes in Behaviour

Changes in behaviour are very common when people have dementia. There is always a reason for behaviour and it is important to remember that all behaviour is a form of communication. It might not immediately make sense, but with some observation and a bit of detective work, the cause is usually identifiable.

It's hard you know, trying to figure out what's going on, it's like he's had a whole personality change.

As the memory rolls back, being in the here and now becomes much more difficult. The person may revert to old habits and routines, which might seem strange but will be meaningful to the individual. Unless they are potentially harmful behaviours, it is best to go with them. Many people can be distracted after a few moments.

She would spend ages rooting in the cupboard for a carrier bag, then when she found it, she'd scrunch it up and put it back in there, but she would be very annoyed if you tried to stop her.

One night after tea, he came into the kitchen and insisted on washing up—he hadn't done that for years.

Every night, he packs a bag and puts it under his bed—it took a while before his brother told us that he used to stay in a residential unit from Monday until Friday morning so on Thursday night he used to pack his bag for his weekend at home.

Sometimes behaviours are more difficult to deal with but using a calm and reassuring approach, using clues to help the person understand what is happening and going with that person's reality can all help to maintain the person's equilibrium.

Getting out and about

Enjoying being out and about is an intrinsic part of living well with dementia. No one should be cooped up inside all day, some activity and being in the fresh air may even help the affected person to sleep better at night.

Sometimes, she takes a bit of cajoling but when we do get out she usually loves it and doesn't want to come back in once we get home.

One of the issues can be that the person does not know what to expect, giving them lots of different clues can help. For example, a trip to the shops could be achieved by giving the person a shopping bag and his/her purse or wallet and perhaps a list of things to buy. It does not matter if he or she can no longer read the list, it is simply a visible and tangible clue about the activity that is going to happen.

He loved going to the local football matches but had become very resistant to it and would say no, stay here when we talked about it. We got round it by having the sports programme on TV in the morning, listening to the radio in the car, making sure he was wearing his team shirt and scarf and giving him an old match programme to carry. That seemed to help him tune in to where we were going. Once we were in the ground, he responded really well to the noise and joined in the chants and football songs.

Mixing up day and night

Night time waking is very common for people with dementia and can be the first cause of difficulty in maintaining a placement if the cost of waking night staff cannot be met. Trying to establish a good bedtime preparation routine can be beneficial.

We used to make sure that he was dressed in his clothes during the day and distracted him from putting his pyjamas in until a reasonable time in the evening. Nearer to bedtime, we would encourage him to have a bath, help him make a hot chocolate and turn the telly volume down. He liked to sing along to nursery rhymes so we bought him a CD and we would have that playing when he got into bed. It didn't work every night but more often than not it did.

Living in supported accommodation

Many people with Down syndrome live in supported accommodation and may have been in their home for many years before the dementia onset. Often, there is a willingness to continue to support an individual and adaptations are made to assist this. Training staff teams to understand how dementia affects a person is paramount. This will reduce any fear and anxiety they may have. It will also give an opportunity to share ideas and highlight any issues currently being faced so that strategies can be agreed.

Sadly, as the individual's support needs become more intense there can be problems with securing additional support packages such as the need for waking night staff.

There are some intellectual disability organizations that recognize the continuing and increasing needs of their tenants with Down syndrome and dementia and are now setting up dementia-friendly services. This is to be commended.

Unfortunately, it is still very common for people to have to move from their home into a Nursing Care Home or Elderly Mentally Ill setting as the dementia progresses. This move is often very difficult for relatives and intellectual disability staff teams to accept and cope with, causing a great deal of stress and anxiety.

As time has gone on, they have made adaptations and increased staffing levels but the nature of the building is just not conducive to catering for her longerterm needs. The increased care package is more expensive and we have been asked to look at alternative placements.

My sister is in hospital as her seizures have increased and I need to find a new care home, I don't know where to start looking.

We have a brother who is 53 and who has lived very happily in an 'assisted living' home with three other men with intellectual disabilities. Unfortunately his condition has deteriorated quite severely in the last month and we have been advised that the home feels that his needs are now beyond those which they can accommodate.

A lady who has lived here for 26 years has just been moved because of her increased care package. There was nothing we could do. We have four other people with Down syndrome living here, they are very concerned.

Even with the best will in the world, finances often play the decisive role in deciding where someone with Down syndrome will be placed in the later stages of dementia. It is important that relatives are part of this process and are involved in locating the most suitable place available.

As of today social services have informed us that a place has been reserved at a residential Care home with an EMI unit and we have no option but to go with this since they say that his assisted living residence can no longer cater for his needs. There does not seem to be any targeted provision for such people in his area. As for everyone in this situation, it is a particularly difficult time, but my sister and I did go and visit this place today, and it did seem to have a good caring feel.

Remaining in place

For those who do remain in place, relatives and staff teams report some satisfaction in being able to look after the person until the end of their life. Recognizing that support from other intellectual disability and palliative care professionals is an intrinsic part of ensuring that the individual remains comfortable in the late stages of dementia and can reassure carers that they are doing the best for their loved one or person they are looking after.

> *It was very hard, quite exhausting to be honest but we wouldn't have had it any other way. She seemed to know us right until the very end and we just knew that she felt safe and comfortable in familiar surroundings. It was very peaceful at the end and we've all agreed that we will do the same if it happens to anyone else.*

Life expectancy in Down syndrome

Several studies have shown substantially longer survival for people with Down syndrome in recent decades (Zhu et al. 2013). Presson et al. (2013) comment that median life expectancy increased from 25 to 50 years in the US population between 1983 and 2000 and from 24 to 52 years in European studies. This is due primarily to a dramatic decline in infant and child mortality, especially in children with congenital heart disease (CHD). As we will see in Chapter 8, early identification and intervention in CHD significantly improves outlook.

The life expectancy of older people with Down syndrome has improved over a similar period but far less markedly. Zhu et al. (2013) report a mortality of 5–11 times that of the general population, similar to other studies. There is better survival for people with mosaicism than for people with standard trisomy 21 or translocation Down syndrome. Day et al. (2005) reported that leukaemia (standardized mortality ration [SMR] = 17), respiratory

Table 4.1
Age distribution prevalence of people in 2011 with Down syndrome in England and Wales

Age in years	*Number of people with Down syndrome (%)*
0–9	6145 (16.57)
10–19	5480 (14.77)
20–29	5803 (13.70)
30–39	5829 (15.71)
40–49	7862 (21.20)
50–59	4475 (12.07)
60–69	1403 (3.80)
70+	93 (0.25)
Total	37090

illnesses (SMR = 27), congenital anomalies (SMR = 72) and circulatory diseases (SMR = 5.3) accounted for most of the excess mortality not attributable to CHD. With the exception of leukaemia, cancer mortality was not different from that of the general population. Despite the improvements in medical care conferring significant benefit to younger people, brain degeneration continues to limit longevity. Alzheimer disease brain degeneration leads to a gradual decline in intellectual and physical function and the great majority of people with Down syndrome do not survive beyond age 70.

This is shown in Table 4.1 that displays data adapted from Wu and Morris (2013). The sharp fall in the population prevalence of people with Down syndrome after the age of 60 can readily be seen. So, the picture is changing and improving with survival into the late 50s and 60s to be expected for most, but the life-limiting influence of Alzheimer disease is yet to be overcome.

Note

1. NFER: Young people with special educational needs/learning difficulties and disabilities: Research into planning for adult life and services, Kerry Martin, Ruth Hart, Richard White and Caroline Sharp Research Report, September 2011, http://www.nfer.ac.uk/publications/SENT01

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RESOURCES

New parents

Down's Heart Group: http://www.dhg.org.uk/.

UK Down's Syndrome Association Helpline: http://www.downs-syndrome.org.uk/information.html.

Developmental progress preschool and school years

Many parents and practitioners use Early Support information and development resources to help them understand children's development, share successes and inform next steps in development.

Early Support information resources help practitioners to answer the questions parents are most likely to ask either at the time of diagnosis, soon after or as the child grows and matures. http://www.ncb.org.uk/early-support/resources/information-resources.

Early Support developmental journals are designed to help families and practitioners improve their encouragement of development with easy to use tools to help with observing, recording and celebrating progress, and to identify areas where extra help and support may be needed. The main body of each journal consists of milestones that parents and practitioners can easily observe in the course of everyday life. The journals provide information on development and allow families to build a record of achievement for their child. http://www.ncb.org.uk/early-support/resources/developmental-journals.

The developmental journal for babies and children with Down syndrome has eleven steps, each of which describe typical patterns of development in five main areas: communication, social-emotional, cognition and play, motor and sensory and self-help. http://www.ncb.org.uk/early-support/resources/developmental-journals/developmental-journal-for-babies-and-children-with-down-syndrome.

The developmental journal for children and young people with multiple needs can help families and practitioners support the development of children who have Down syndrome and additional needs. http://www.ncb.org.uk/early-support/resources/developmental-journals/developmental-journal-for-children-and-young-people-with-multiple-needs.

There are also developmental journals for deaf infants and infants and children who have visual impairment.

Adolescence and transition

Terri Couwenhoven (2007) *Teaching children with Down's syndrome about their bodies, boundaries and sexuality: A guide for parents and professionals. Topics in Down's syndrome* (Bethesda MD, Woodbine

House). A useful, thorough guide to helping children and young people with Down syndrome understand about puberty, sexuality, relationships and every other aspect of growing up. Has a useful section on self-talk.

Dennis McGuire, Brian Chicoine (2006) *Mental wellness in adults with Down syndrome* (Bethesda MD, Woodbine House). An easy-to-read guide on what the common behavioural characteristics of Down's syndrome are, how some could be mistaken for mental illness and what actual mental health problems occur more commonly in people with Down's syndrome.

Brian Chicoine MD (2010) *Guide to good health: For teens & adults with Down syndrome* (Woodbine House 2010). An excellent guide to health, healthy living and nutrition for parents and carers of young people and adults with Down's syndrome.

Asking for a Community Care Assessment, Preparing for a Community Care Assessment and Getting the Care Plan Right. DSA Community Care Assessment Guides: http://www.downs-syndrome.org.uk/.

Some sexual health issues
Sexual health (a guide for parents and carers) available to download from DSA website. http://www.downs-syndrome.org.uk/download-package/14-sexual-health/

Adult life with Down syndrome
DSA Annual Health Check Information for GPs
http://www.downs-syndrome.org.uk/for-professionals/health-information-for-medical-professionals/annual-health-check-information-for-gps/

DSA Health Book for People with Down Syndrome
http://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/annual-health-checks/

Royal College of General Practitioners (2010) A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability, http://www.rcgp.org.uk/learningdisabilities/