



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Health Alert! Campaign



Health care for people with Down's syndrome

The Down's Syndrome Association is the only charity in England, Wales and Northern Ireland focusing solely on all aspects of living successfully with Down's syndrome.

Established in 1970, we will shortly be celebrating our 50th Anniversary. We have around 20,000 members throughout England, Wales and Northern Ireland. The Association is in contact with over 130 local Down's syndrome support groups and a range of professionals from different agencies. The aim of the organisation is to help people with Down's syndrome lead full and rewarding lives.

The DSA is the lead provider of information, advocacy, support and training to anyone with an interest in Down's syndrome. We are a membership-led organisation, with our membership comprising family-carers (parents) of children and adults with Down's syndrome, professionals, and a growing membership of adults with Down's syndrome aged 18+. We are well placed to reflect the needs, attitudes and opinions of people we seek to serve.

Stop Press: We have been alerted by a sibling to the recent death of her brother in his early forties. They have told us about their serious concerns relating to the care their brother received prior to his death. We have written to the Chief Executive of the relevant NHS Trust raising those concerns and offering to work with the Trust to ensure people with Down's syndrome receive equitable, timely and high-quality healthcare. 14 November 2019

About Down's syndrome

Down's syndrome is a genetic condition, caused by the presence of an extra chromosome 21 in the body's cells. Everyone with the condition will have some degree of learning disability. In addition, there are a number of associated medical conditions, which affect some, but not all, people with Down's syndrome, meaning the services that they access from the NHS (and social care settings) are of paramount importance to their wellbeing.

The number of people in England and Wales with the condition was estimated at 37,090¹ in 2013.

Barriers to good healthcare for people with Down's syndrome

- Lack of understanding among health professionals about Down's syndrome and the more common health conditions in this group of people.

¹ Wu J, Morris JK The population prevalence of Down's syndrome in England and Wales in 2011 Eur J Hum Genet 2013 Sep; 21(9):1016-9. doi: 10.1038/ejhg.2012.294. Epub 2013

- Diagnostic overshadowing by health professionals where symptoms of illness are attributed to a person having Down's syndrome and therefore not properly investigated.
- People are less likely, or able to, self-report health issues.
- More likely to be reliant on family/supporters to maintain good health.
- Difficulties with spoken language and communication.
- Difficulties describing and locating pain/illness in the body.
- Difficulties with short-term auditory memory making it harder to take in information through hearing.
- Hearing and sight difficulties are common.

We've come a long way

It has long been recognised that people with Down's syndrome experience poorer health outcomes than are seen in the general population.

We published a report in 1999 on a survey of our members about discrimination against people with Down's syndrome by medical professionals called "He'll never join the Army". It showed that a significant proportion (28%) of parents/supporters of people with Down's syndrome felt that they had encountered discrimination on the grounds of disability.

At around this time, we launched our original Health Alert campaign to raise awareness amongst health professionals of the health needs of people with Down's syndrome. As part of this campaign, we collaborated with St. Georges Medical School, London to produce a website for health professionals to promote access to healthcare in an equitable and timely manner.

Since then we have worked very hard, with support from the UK Down's Syndrome Medical Interest Group, to improve health care for people with Down's syndrome.

We have:

- responded to Government/NHS consultations
- produced an increasing range of health-related resources
- disseminated information about best practice
- given assistance to family carers and supporters via our Helpline
- provided training to health care professionals

Consequently, there have been many positive developments around awareness of the health conditions more common in people with Down's syndrome and their treatment. With appropriate and timely healthcare, more people with Down's syndrome are now living in to their 50s and 60s and a small number in to their 70s and beyond.

"We have excellent health care from our daughter's GP, Out of Hours and also from her heart consultant and rheumatologist."

"I would like to say how much we have appreciated the care our son received. I know the NHS gets some bad press and not everyone has good experiences but I felt it was important to report a positive experience!"

"Fingers crossed and touch wood all the professionals he has been involved with have always shown great care and understanding."

"We have had nothing but excellent care from the NHS throughout his life (he is 21 years old). Our own local GPs have been exceptional in their care and consideration. We have nothing but praise and thanks for the care he has received."

More widely, health professionals now have a duty to make reasonable adjustments for their patients with disabilities to ensure they have the same access to health care as everyone else. For people with Down's syndrome, reasonable adjustments may include longer appointments, easy read information and support around consenting to treatment. See Annex A for further examples of reasonable adjustments in healthcare settings.

But we still have serious concerns – one preventable death is one death too many

Despite our concerted and ongoing efforts in the field of healthcare and the positive developments we have witnessed, there have been a number of recent high-profile distressing cases of preventable deaths of people with Down's syndrome.

DSA statement on the death of 'Jo-Jo' from Hackney. 26 July 2019

The Down's Syndrome Association is horrified by the details revealed today about the death of 'Jo-Jo'.

It is appalling to read about yet another person who had Down's syndrome, and their family, being let down by the health and social care agencies that were supposed to be supporting them.

The Safeguarding Adults Review published in June 2019 concludes that:

"The evidence and information gathered in this review and the LeDeR process outlines the ways in which both Jo-Jo and her mother, as the main carer, were let down by a succession of gaps and omissions by health and social care agencies on many occasions. Many simple straightforward communications/basic activities were not carried out, no one sought to coordinate care, good practice was ignored, policy and current learning was ignored, and unrealistic and untested assumptions were made about Jo-Jo's mother, who was left virtually unsupported to provide daily care for her daughter's undiagnosed skin condition....Jo-Jo's care was not impaired by the lack of resources, rather she (and her mother) were left isolated by poor and ineffective use of resources...It is difficult not to conclude that her learning disability played a part in these gaps and omissions."

As we have said before, the DSA is gravely concerned that, in the twenty-first century some individuals who have Down's syndrome are being denied good quality care. These failings represent a human rights outrage.

Shockingly, we are still hearing some of the things we heard back in the 1990s:

1990s or 2019? A selection of quotes from the 1990s and the present day

"An eye doctor was unsure of sight loss and said to a nurse in front of me – 'never mind, it doesn't matter - she has Down's syndrome'."

"He (the consultant) didn't feel the removal of the cataracts would be good value for the NHS as my son didn't drive or read books and he felt the cost was better spent on someone else (i.e. normal). His words."

"Professionals don't bother to communicate with him and decline to discuss things with us or gloss over particular concerns."

"During a recent hospital stay for a severe gastric episode, the communication protocol from hospital staff was poorly managed. Necessarily, my brother was alone in the hospital"

"GPs at the surgery are also not always approachable - we feel rather "bawled off" at times"

The LeDer Programme

In a House of Commons debate (May 2019) about the Learning Disabilities Mortality Review (published by the LeDeR programme) Norman Lamb MP said:

"I welcome the Minister's clear statement that it is wholly unacceptable that people with learning disabilities continue to experience much shorter life expectancy. It is wholly unacceptable, but the problem is that we have all been saying this for years and nothing ever changes. We do not appear to be capable of learning the lessons that she says are necessary."

Work on the LeDeR programme by the University of Bristol commenced in June 2015, initially for three years. Their contract currently runs until the end of May 2020.

Its overall aims are to:

- Support improvements in the quality of health and social care service delivery for people with learning disabilities.
- Help reduce premature mortality and health inequalities for people with learning disabilities.

The LeDeR programme supports local areas in England to review the deaths of people with learning disabilities (aged four years and over) and to take forward any lessons learned in the reviews to make improvements to service provision. The LeDeR programme also collates and shares anonymised information about the deaths of people with learning disabilities so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements.

Our members' experience of healthcare

In response to the news of the recent preventable deaths, we asked our members to let us know about their experiences of healthcare for the person with Down's syndrome they support.

At the time of writing, we have received reports (See Annex B for examples) from DSA members containing examples of poor healthcare involving people with Down's syndrome. The reports carry several worryingly familiar and common themes; these are summarised below (text in italics within boxes are direct quotes from family-carers). We will continue to collect information from our members about their experiences of health care.

Family carers feel their role in healthcare settings is ambiguous and that they are sometimes dismissed and ignored. Some family carers worry about what will happen to their relative's health when they are no longer around to provide support.

"Found hospital staff very abrupt/unsympathetic at times."

"I have no doubt that once I am no longer around to provide and co-ordinate all my son's health needs, he will not be able to access the care he needs and will undoubtedly have his life shortened as a result."

Most adults with Down's syndrome live with their family although small but increasing numbers of people are leaving home to live with support in their communities. Therefore, many people with Down's syndrome will rely on family to recognise when they are unwell, to support them to access good healthcare and to act as intermediaries in healthcare settings. Families will possess extensive knowledge about their family member with Down's syndrome, which will be useful to healthcare professionals in ensuring the person is properly supported whilst in their care to receive appropriate and timely healthcare. Those who know the person well will have valuable information about signs of anxiety/distress, communication and support needs and well-tried methods of providing reassurance.

An obvious point, but one which needs to be stated, is that families who have contacted their GP or taken their loved one to a healthcare setting will very likely be anxious and worried about them. Whilst not detracting from the rights of the person with Down's syndrome around their privacy and making decisions, family carers should be listened to and treated with respect.

Diagnostic overshadowing, assumptions about people with Down's syndrome coping with aftercare following surgery and disability discrimination

Health professionals must regularly reflect upon their attitudes and practice in order to guard against making assumptions about individuals with Down's syndrome in their care. People with Down's syndrome have a right to equitable and timely healthcare.

"Diagnostic overshadowing occurs when a health professional makes the assumption that a person with learning disabilities' behaviour is a part of their disability without exploring other factors such as biological determinants. Diagnostic overshadowing has been defined as 'once a diagnosis is made of a major condition there is a tendency to attribute all other problems to that diagnosis, thereby leaving other co-existing conditions undiagnosed.'"²

"The doctor left the room to get a form signed. When she came back in she said 'It's no good, we don't do it for people like him'."

"We were referred for cataracts by Specsavers to the hospital. The nursing staff were excellent but the consultant was very rude and impatient not explaining before he sprayed air into my son's eyes and said he didn't feel the removal of the cataracts would be good value for the NHS as my son didn't drive or read books and he felt the cost was better spent on someone else (i.e. normal). His words."

"When my daughter was at her previous surgery, abnormal thyroid results were ignored. She subsequently became severely depressed, lost a large amount of weight (down to 5.5 stone) and became tachycardia."

"If Mum had not persevered, I doubt the surgery would have happened. GP tried too. I felt that I had to provide evidence of successful outcomes of total hip replacements in people with Down's syndrome as surgeon questioned post-op need."

Recognising and managing pain

People with Down's syndrome may have difficulties effectively communicating their pain and its location to others. Pain may not be understood or communicated as pain but as another feeling such as discomfort or worry. Changes in behaviour may indicate that a person is in pain. There has been a suggestion, although based on limited evidence, that "people with Down's syndrome may be more sensitive to pain but with a delayed pain expression"³.

² Diagnostic overshadowing: See beyond the diagnosis by Jim Blair, Consultant Nurse, Learning Disabilities, Great Ormond Street Hospital, Associate Professor, Learning Disabilities, Kingston and St. George's Universities <http://www.intellectualdisability.info/changing-values/diagnostic-overshadowing-see-beyond-the-diagnosis>

³ Pain experience in adults with Down syndrome, Nana de Knecht PhD, Clinical Neuropsychology Department, VU University, Amsterdam, the Netherlands. T21RS Science & Society Bulletin, 2016 (1)

"My brother describes pain in a different way to those without learning disability (bottom/silver pipe) 'It's an apple in my bottom'...I don't like it (pain)"

"Indifferent attitude to patient pain communication leading to more than one episode of acute constipation causing further bladder pain leading to pain from catheter. This surely is basic medical care. This will lead (my brother) to fear future admission/repetitive cycle."

Lack of empathy/compassion from healthcare staff for family member with Down's syndrome

Patients with Down's syndrome and their families should be treated with dignity and respect. Healthcare must be provided on an equitable basis with healthcare staff being mindful of the human rights of their patients with Down's syndrome.

"My brother has profound difficulty in comprehending and communicating. During a recent hospital stay for a severe gastric episode, including emergency treatment, the communication protocol from hospital staff was poorly managed. Necessarily, my brother was alone in the hospital and during this time had been misinformed of the nature of his ailment. An understanding that he would be unable to comprehend, this misdiagnosis led to unnecessary anxiety for the whole family."

"Indifferent attitude to patient pain communication leading to more than one episode of acute constipation causing further bladder pain leading to pain from catheter. This surely is basic medical care. This will lead (my brother) to fear future admission/repetitive cycle."

"My son broke his ankle when he was at college. He was about 19/20. We got there as soon as we could. We found he was in a geriatric ward and they were giving him drinks in a Tommy Tippy Beaker!! They had no idea how to deal with him, so I stayed by his bedside 24/7 for 4 days. They were giving him morphine, which was making him terribly sick but when I told them to stop, I was told he asked for pain relief and when offered he said yes! They took no notice of me at all as they said he was over 18."

"I haven't had any specific concerns, but my daughter has a high pain threshold. However, I believe this is due to her learning disability and non-verbal communication so healthcare professionals perceive that she is not experiencing pain due to her slow/let response to it."

It is vital healthcare professionals have a grounding in the learning strengths of, and challenges experienced by, people with Down's syndrome so they can make appropriate reasonable adjustments and provide equitable and timely healthcare in a sensitive and supportive manner.

Lack of understanding of statutory guidance around decision making and mental capacity

Calls to our Helpline indicate this is a common problem. It is imperative people with Down's syndrome are properly supported to make decisions about their healthcare where they can and, where they cannot, statutory guidance⁴ is strictly adhered to.

In the past, people with learning disabilities often had decisions made for them, which led to a lack of control in their lives and enabled things like financial abuse and forcible treatment to occur. The Mental Capacity Act (MCA) (2005) attempts to address this situation by providing a common-sense approach to supporting people in making their own decisions when they are able and to protecting their interests if they can't make specific decisions for themselves. The MCA Code of Practice provides guidance for decisions made under the Act. It gives guidance to people whom:

- work with people who can't make decisions for themselves
- care for people who can't make decisions for themselves

It says what you must do when you act or make decisions on behalf of people who cannot act or make those decisions for themselves.

"Initially my son was referred to our local hospital. We saw a consultant who was off-hand and uninterested in my son and the questions I had. I advised him we would need a Best Interest meeting with Learning Difficulties Team involvement and taking their advice on sedation, before we could proceed. A month later, a letter arrived with an appointment for the procedure. I contacted the hospital to advise that certain steps needed to be taken before my son could undergo the procedure, given he does not have capacity. Sometime later another appointment arrived for the procedure to be done. At that point I asked my GP to refer him to another hospital.

This experience really brought it home to me how vulnerable people with learning disabilities are when it comes to health care. My son was OK in the end as he us to advocate for him. If he had been a person without family support things could have turned out very differently. The first hospital clearly had no framework in place regarding people lacking capacity. In the end, my son was extremely distressed and his behaviour needed extremely careful and co-ordinated approaches. He ended up in Intensive Care and I hate to think what may have happened if he had not had the opportunity to be treated at a hospital that does have protocols in place that are followed and has a pro-active Learning Disability Team. We were also followed up after we were home by the "Enhanced Recovery Team" who were there for advice and support for 2 weeks post discharge."

From General Medical Council (GMC) guidance:

'You should check whether the patient needs any additional support to understand information, to communicate their wishes, or to make a decision...make sure, wherever

⁴ Mental Capacity Act 2005 Code of Practice (2007)

practical, that arrangements are made to give the patient any necessary support...
(Consent, paragraph 21)

Lack of reasonable adjustments in healthcare

Public services are required by law to make reasonable adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act 2010 to make reasonable adjustments applies if you are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you. For people with Down's syndrome reasonable adjustments may include easy read information, longer appointments, clearer signs at the practice, help to make decisions, changes to policies, procedures and staff training to ensure that services work equally well for everyone. See Annex A for further examples of reasonable adjustments in healthcare settings.

"GPs - pathetic annual health check. Bare minimum despite taking check line from DSA. No flexibility i.e. appointments - offered morning ones despite it being recorded we can only access pm."

Communication

Communication in a healthcare setting is an important part of patient safety and quality of care. There is a sense from the reports we have received that communication failure is a very common experience, be that communication between healthcare professionals, communication with families/supporters and/or communication with patients with Down's syndrome.

"The General Medical Council (1993) consider effective and sensitive communication to be one of the "essentials of basic clinical method". "Doctors must be good listeners if they are to understand the problems of their patients and they must be able to provide advice and explanations that are comprehensible to patients and their relatives".

In 2001, the GMC augmented this with an outline of what constitutes good clinical care: "proficiency in communication skills, including the ability to obtain and record a comprehensive patient-centred history... professional attitudes and behaviour that facilitate effective and appropriate interaction with patients and colleagues ... Demonstrate respect for patients and colleagues that encompasses, without prejudice, diversity of background and opportunity, language, culture and way of life..."⁵

⁵ Clinical communication by Alice Thacker <http://www.intellectualdisability.info/how-to-guides/articles/clinical-communication>

"It was very clear that the main issues were the lack of communications between all teams and the fact that still after all this time there was no clear care plan."

"My brother was repeatedly spoken to in unacceptable language - ranging from questions he would not understand; 'have you opened your bowels recently' to lack of communication about pain; to asking him if he was 'going to be a good boy today?' He is 63."

"Poor information sharing with family and recognising carer support. Patient did not receive all his meds and was without Thyroid medicine for 4 days after admitted to ward. This was only picked up when I asked why he looked so exhausted and noted his continued lack of engagement."

"He was taken for an x-ray and not spoken to by the porter - nor explained beforehand where he was going. Not even introduced himself by name."

"My brother was admitted with care passport (provided in paper form on admission). This holds detailed information about health and welfare as he is unable to communicate health related information. This was regularly ignored, and information was not shared with other staff at changeover."

Poor communication may lead to errors in treatment and care, in some cases potentially life threatening, and cause misunderstandings, anxiety and suffering for patients with Down's syndrome and their families/supporters. In 2008 the *Healthcare for All Report* stated:

"Partnership working and communication (between different agencies providing care, between services for different age groups, and across NHS primary, secondary and tertiary boundaries) is poor in relation to services for adults with learning disabilities. This problem is not restricted to services used by people with learning disabilities but particularly affects those who may not be able to communicate for themselves, or whose treatment needs careful planning and coordination because they have complex needs."⁶

It is unacceptable that communication problems of this nature are still occurring in the healthcare of people with Down's syndrome a decade after the *Healthcare for All* report.

DSA Actions

- Submission of our response to The Department of Health and Social Care consultation on mandatory learning disability training for health and care professionals (April 2019). **As our consultation response states, the call for mandatory learning disability training for health professionals is welcome, but by no means all that is needed.**
- DSA has been involved in shaping National Institute for Clinical Excellence (NICE) guidance around growing older with a learning disability. We responded to a

⁶ Healthcare for All: Report of the independent inquiry into access to healthcare for people with learning disabilities (2008)

consultation on developing new standards for services to adopt. The guidance was published in July 2019.

- We are looking at developing a Down's syndrome specific training package for health care professionals (2019/20)

The DSA will continue to inform, raise awareness and campaign about the health needs of people with Down's syndrome and their right to equitable and timely healthcare.

Annex A: Examples of reasonable adjustments in healthcare settings

Hospital passports / communication passports / DSA's Health Book

Offer appointments at times of day when surgery perhaps less busy – first or last appointments

Provide longer consultation periods than would normally be offered

Speak to care giver prior to appointment to find out what works best for person with a learning disability – do's and don'ts

Offer visit prior to appointment (s) to familiarize person with the environment

Progressive familiarization of the environment and the removal of cues that may be associated with earlier negative experiences (e.g. the wearing of white coats)

If possible, ensure continuity of care with the same GP / Nurse

Try to minimize waiting periods

Good signage – colour coding and the use of pictures and symbols may be beneficial

Where possible, reduce distractions in the physical environment

Identify self to patient each time you meet them

Speak directly to the patient, even if they cannot verbally respond, and then the supporter (if present)

Allow patient to express their problem / experience / perceptions in their own way

Explain the process of the consultation before you start

"I need to listen to what you say about why you have come to see me"

"I may need to look at the part of you that hurts."

"I will think about what is the matter with you."

"I will tell you what we will do next."

Allow the patient to hold/touch any equipment before use. People with learning disabilities may be, because of previous experiences, frightened of some of the equipment used in medical examination. Before you do anything to the person with learning disabilities, show them what you are going to do. Tell them why you are going to do it, and why you are using the instrument that you are going to use on them. Tell them if you think it might hurt. Then ask the person with learning disabilities if they understand what you are going to do. This way you can gain consent as you progress with the patient continuing to co-operate with the check.

Do not assume that the person will understand the connection between the illness and something they have done or something that has happened to them. People with learning disabilities may not make connections between something that has happened and their illness or their body and feeling poorly.

Be ready to draw explanatory pictures

Use visual cues to explain procedures and to help explain what is going to happen next – reinforce information by repeating/revisiting it where necessary

If drawing internal body parts; always show the body part in the context of the outer body

Provide leaflets with simple clear concise wording – examples to be found at www.easyhealth.org.uk

Use imitation and role modelling to demonstrate a procedure

Demonstrate non-invasive procedure on self or caregiver

If supporter is involved in consultation, observe their interaction with the patient

Think about tone and total communication (e.g. hand signals, facial expressions)

Ask if it ok to touch the patient

Engage the patient in her own health care even if their supporter (if present) has to answer for the person

Think about time references if you are asking about when the person began to feel unwell. Reference an important event in their lives and/or use pictures of going to bed or sunrise to help them to give you an indication of time.

Provide opportunities for the patient to ask questions – this could be done by pointing to possible questions for the person to select from and/or pictures for example.

Use resources to support the patient to better communicate pain, discomfort, something not being right, feelings etc.

Praise co-operative behaviour

Ignore behaviour that may seem out of the ordinary (e.g. self-talk)

To establish understanding invite the patient to say in their own words what you have told them. 'Do you understand' may elicit a compliant 'yes' even where the person has only partially understood or not understood at all.

Ask open questions with plain language supported by visual information where possible. Change your question or information around in order to gauge the level of understanding that your patient has.

Talk about the administration of medication in relation to routine daily events such as meal times

Changes in patterns of behaviour should always signal an alert that all is not well.

If referred to other Health Professionals make sure that they are aware that the patient has a learning disability and that they may need some extra support.

Annex B: Case studies

Case A

My son was referred for endoscopy at Hospital (I didn't realise what was involved!) The nurse who took our details assumed capacity. He said he wanted to go in alone. In my ignorance, I let him. I soon heard him shouting. I was called in. He was lying in a dimly lit room, obviously terrified, with the procedure ongoing. I was very upset to see him like this. So, I followed their instructions and helped to hold him whilst the endoscopy was done. There were three of us holding him. When it was over, he was still upset. The doctor showed me the photos which showed that he has Barrett's Oesophagus. The doctor went on to say that he needed an endoscope every 2 years. He then looked at my son and said 'if you think it's worth it'. I like to think that was because of the trauma it had caused him and not because he has Down's syndrome! Since this happened we have been allocated a learning disability nurse to support us with medical appointments and his forthcoming cornea transplant. We have also spoken to an anaesthetist who has approved the use of general anaesthetic for future endoscopies.

Case B

My son has had nystagmus since he was 6 months old and was under the hospital for eye checks. When he was discharged his care moved to the optician because he lost or broke his glasses several times a year and they were free here. After one eye test when he was a young adult, I decided to take him to my optician because they did an adult test, nothing simplified, no extra time allowed and I knew by his answers he did not fully understand the questions.

My optician was brilliant with him and diagnosed keratoconus and was very surprised this wasn't picked up before! We were referred back to the hospital and suddenly I found that my son was partially sighted - I never knew. I knew he didn't have 20:20 vision but never realised how poor it was. We also found out that glasses make no difference - all that wasted time getting him to appointments at the hospital were never good, no extra time allowed, no-one speaking to him except to give an instruction etc. My optician told me about an operation called collagen cross linking which could halt further deterioration in his good eye (he can't see much with his other eye). Two years ago I mentioned this at his annual hospital appointment. The doctor left the room to get a form signed. When she came back she said 'it's no good, we don't do it for people like him'. I took my son to a private appointment (£150) where everyone treated him wonderfully and gave him plenty of time. This was used as a baseline.

A year later we had another NHS appointment and I again asked about the collagen cross linking. The young man, a student, left the room and came back to say 'they won't do it because he has Down's syndrome'. I said 'surely it matters more that he is losing his sight?' but he wouldn't budge. Luckily I had taken the Learning Disability Nurse with me so I have an independent witness. She was shocked! The letters from the hospital after these appointments did not reflect what was said.

So another private appointment and the consultant agreed there was a deterioration in my son's sight so he agreed to do the operation. It went well and has halted the deterioration in his good eye and even improved it slightly.

It was the best £1550 we have ever spent! The consultant also said my son should never have been seen by a Year 7 student because his is a complex case.

I feel that the NHS would have let my son go blind because of his disability. God help people who do not have someone with the where-with-all or the money for private care.

Case C

My son has profound difficulty in comprehending and communicating. During a recent hospital stay for a severe gastric episode, including emergency treatment, the communication protocol from hospital staff was poorly managed. Necessarily, my son was alone in the hospital and during this time had been misinformed of the nature of his ailment. An understanding that he would be unable to comprehend, this misdiagnosis led to unnecessary anxiety for the whole family.

Case D

Difficulty in persuading surgeon that the problem was her hip, speed of her decline, depth of her pain and that surgery was necessary, during which time she suffered greatly and had no quality of life, unable to leave house. Mum's advocacy on her behalf was questioned by the surgeon. If Mum had not persevered I doubt the surgery would have happened. GP tried too. I felt that I had to provide evidence of successful outcomes of total hip replacements in people with Down's syndrome as surgeon questioned post-op needs, so I contacted DSA and DSMIG as they said there was an increasing number of people with Down's syndrome needing replacements and these were successful.

GP had tried but making little impact. Daughter in terrible pain, not able to walk, analgesia ineffective. Support provider staff (where involved) cannot "advocate" for a disabled person in the way that family can. They must accept what the professional is saying. This means that less favourable support may be offered. Underlines how important the role of families/advocates can be in these situations.

Case E

My adult son (recently deceased) had learning disabilities and mild mental health conditions. Ten years ago he was diagnosed with kidney failure which eventually necessitated him going on to dialysis. He lived with his wife out 'in the community'. She also had learning disabilities and manic depression. We were told he did not qualify for a kidney transplant because he was refusing to dialyse regularly and therefore would not take on board a strict medication regime, post-transplant, to stop the new kidney being rejected. He was only in his late 30s.

Patients in their 60s were being offered transplants! He managed to live a moderate life for several years, then last year went rapidly downhill and died. I do feel, and put it to one of the senior doctors quite recently, that the real reason he was refused another kidney was because of his learning disability and mild mental health problems. He told me that 'I can't answer that'.

NB I made him attend his outpatient appointments regularly because I and his wife went with him to make sure he did attend. He was reasonably fit in those days 4-5 years ago. We are burying him next Wednesday. He was 45.

Case F

My concern is for many of our adults who live in supported living often with no overnight care. My son has a stoma. He had food poisoning and he knew he had to get to the hospital. I was on holiday. It was a Sunday evening and there were no carers in his house. He dialled 999. The person who answered the phone must not have realised that he was disabled, referred him to 111 who offered an impossible solution. Finally, his carer was involved and at midnight an ambulance took him to hospital. When I queried this with the Ambulance Service they said they had no instructions about receiving a call from a disabled person and would not have asked him any personal questions or if he was alone. Is this common? If so, it makes a big gap in the ambulance service provision.

Case G

The information here is taken from a Coroner's report sent to us by the father of a woman who passed away age 42 in 2017 from bilateral pulmonary emboli that arose from deep venous thrombosis in the right calf.

There had been discontinuance of anticoagulation treatment regimen during an admission to hospital because of the risk of falls. In 1997, she was prescribed anticoagulation for life. In the light of a number of serious oversights, including:

- no follow up following discharge to ascertain whether anti-coagulation was further required. After continuous treatment for over twenty years, some follow-up assessment was required; and
- given her condition of Down's syndrome, it was negligent of the staff to give treatment without checking either with her parents or the care home about Julie's health conditions. No such engagement was made by the hospital staff;

the Coroner concluded:

"This was an avoidable death consequent on ignorance of the medical facts, poor medical diagnosis and negligent treatment."

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

Contact us

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