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No laughing matter

When my son Daniel experiences pain his reaction is often to laugh

Daniel has severe learning disabilities and I always make sure that staff supporting Daniel know about this unusual pain indicator so that they can be on the lookout for any health issues that may need addressing. In doing this I am acutely conscious of how easy it can be to miss the health needs of someone like Daniel who cannot communicate verbally.

In this issue of ‘Challenge’ we are highlighting health issues and the importance of being aware of the health needs of those we care for. We have also produced a new information sheet on this important subject (page 5). Mencap’s recent report, ‘Death by indifference’ makes shocking reading (page 4). People with learning disabilities have a right to the same health care as anyone else, yet the reality is that often their health needs are not being met.

Daniel recently underwent major surgery. He had scoliosis (curvature of the spine) and we were told that if left untreated it would begin to affect his breathing and his movement.

In some ways it would have been easier not to have the operation, but that would have inhibited Daniel’s future. Daniel is very active, and enjoys long (fast!) walks, so not taking any action would have seriously restricted his quality of life. Our attitude was that it had to be done, and we all had to deal with it.

Daniel was in the operating theatre for six hours, intensive care for two days and twelve more days in hospital before he was able to return home. A great deal of time and effort was put into organising round-the-clock additional support staff, ensuring that Daniel was given the right level of information at the right time and that staff at the hospital knew what to expect.

I am acutely conscious of how easy it can be to miss the health needs of someone like Daniel who cannot communicate verbally.

The hospital staff were excellent, but despite our best efforts some were still completely unprepared for the fact that Daniel could not communicate verbally, would not necessarily take medication if asked to – or that he would eat items such as name bands if they were put on his wrists! There were some difficulties, but fortunately the hospital staff were good at listening to us when we told them something was wrong, even though Daniel did not react in a typical way – for example, laughing while being in great discomfort.

The operation was a success. It was a success not only due to the skill of the surgeon, but because a lot of people put in a lot of time and effort to ensure that the process was as smooth as it could be for Daniel, to ensure that Daniel’s health needs were met – as they should be.

• Vivien Cooper
  Chair of Trustees and Founder of the Challenging Behaviour Foundation

www.challengingbehaviour.org.uk
Physical health issues can contribute to challenging behaviour – but is this sometimes overlooked?

Different professions may view the same behaviour as caused by different things: a psychiatrist may interpret behaviour in one way, a psychologist another, a speech therapist a third, and a doctor or nurse may see physical issues as of paramount influence when trying to account for incidents of challenging behaviour. All these perspectives may be useful in themselves but it is seldom the case that one model explains all.

It does seem rare indeed to find a single simple cause: it tends to be a combination of factors, including biological variables (eg. sensory, genetic, feeling unwell), social and environmental issues (such as learning opportunities, relationships or type of support), emotional factors (well being, opportunities, relationships or type of environment), and cognitive issues (problem solving, communication ability or skills, etc).

Certain conditions are reported to have higher incidence of some behaviours than you’d expect, and thus some conditions are considered to be risk factors for challenging behaviour. These gene-behaviour correlations are studied as behavioural phenotypes. Examples include Lesch-Nyhan, Cornelia de Lange, and Smith-Magenis Syndromes. Though still rare, there are over 750 genetic conditions described, and it’s likely that as our understanding increases we will identify more - and with this describe apparent correlations with functioning and behaviour.

Though some behaviours do seem related to certain conditions (for example Prader-Willi with hyperhagia and food ideation; autism with better visual than auditory receptive abilities), we’re moving from a model known as total specificity (condition X always results in behaviour K and you seldom see behaviour K in any other circumstances) toward a probabilistic model, where the presence of certain genetic omissions, translocations, repeats etc., result in the probable increase of certain characteristics, including certain patterns of behaviour. Not everybody with these conditions shows challenging behaviour (…not everyone with the condition of ‘humanity’ shows the benefits of common sense…), and not everybody who shows challenging behaviour has an identified diagnosis or condition.

Often the basic health needs of people with learning disabilities have been difficult to recognise. Basic health screening and health facilitation is vitally important. If you feel ill you tend not to be particularly positive about things. Getting a good health practitioner on your side can sometimes make all the difference.

This is easier said than done, but following good basic advice on diet and exercise can often help the situation. Eating well, exercising regularly, trying to develop regular routines, all these things can help the person feel better, and you feel you’ve some sort of control. It’s good to have a plan, even if you deviate from it. Any parent knows the stresses of a lack of sleep, and many of us have experienced pain. These things are difficult enough for us to deal with even when we can explain why we feel like we do: I’m fed up and tired but tonight can get an early night.

But imagine not being able to account for how you feel. What if it feels like the pain, the tiredness, the itchiness, the noise in your ears, the ache in your bones - what if it feels like this might never end? Wouldn’t you try to stop it, to escape from the discomfort, in the only way you had? You might develop unusual rituals to help. You might hurt yourself to mask the underlying pain (man, those endorphins!). You might reach out and hurt those around you.

Health facilitation is a crucial element in a growing understanding of how we respond to people’s behaviour: if you feel bad, you won’t take too kindly to be prompted to do your homework, or come do the dishes. So biology is important because it can influence how we respond to people and situations.

So before calling the psychologist or reaching for the 80-page assessment package, think basics - think health and wellbeing.

• Tony Osgood
Lecturer in Intellectual & Developmental Disability, Tizard Centre University of Kent

### Health factors influencing behaviour

Challenging behaviour may be triggered by pain, and a full medical assessment should be undertaken. Health issues that can influence behaviour include the following:

<table>
<thead>
<tr>
<th>1 Pain</th>
<th>8 Hunger</th>
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<tr>
<td>2 Seizure disorders</td>
<td>9 Skin complaints</td>
</tr>
<tr>
<td>3 Infection</td>
<td>10 Otis media (inflammation of the middle ear)</td>
</tr>
<tr>
<td>4 Sleep disturbances</td>
<td>11 Sensory impairment</td>
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<tr>
<td>5 General well-being</td>
<td>12 Medication toxicity</td>
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<tr>
<td>6 Allergies</td>
<td>13 Rhinitis (runny, blocked or stuffy nose, sneezing, etc)</td>
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<tr>
<td>7 Constipation</td>
<td>14 Ulcer</td>
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— Back to Basics —
Q: I have received a referral for a 43-year old man. He has in the past placed shoe laces in his mouth and sucked them, however recently he has started to eat these items. When his laces were taken away he started eating his mattress and quilt cover at night and pieces of carpet. What do you advise?

A1: Someone needs to look into why these behaviours have started or changed recently. It could be that he has a dental or mouth problem that he’s trying to ease, he could be bored or anxious or he may be getting lots of attention for doing it. Perhaps his meal menu has changed and he’s compensating. How’s his appetite lately? Is he gaining or losing weight? Could it be a sign of early-onset dementia? I think the fact that there’s been this apparently “recent” change needs looking into fairly urgently by a specialist clinical psychologist or behaviour nurse therapist. After all, he may choke himself to death on something if someone doesn’t get to grips with this issue.

A2: We have a student who eats paper of all sorts and sometimes stones - avoid as much as possible situations that encourage boredom as this is more often than not part of the reason (in our case).

A3: This is potentially very dangerous, and obviously escalating. Suggest getting urgent input from a clinical psychologist, and in the meantime adjust the environment to keep him as safe as possible (eg. bite proof pillows & duvets).

A4: What diagnosis does he have? Is he overweight? Does he self-injure? As this is a new behaviour I would be looking at doing a full functional analysis using ABC data to try and figure out the setting events and triggers etc. In my experience a new behaviour means he is trying to communicate a need that needs to be figured out!

Q: My three year old has started hitting himself in the head, sometimes quite violently. Someone told me this could be a sign he is in pain – is that correct?

A1: The first step in trying to work out the function of any challenging behaviour is to consider whether pain might be underlying the behaviour. That’s particularly important in self-injury, as painful conditions can lead to brief periods of self injury that may then disappear. Chronic health conditions can lead to longer periods of self-injurious behaviour. Look for other signs of pain such as facial expression (eg. two lines in the middle of the forehead), and get him to a GP to get checked out.

A2: My son, for the first five years of his life, had a lot of sinusitis problems and ear aches that caused him to head bang a lot. Having had several operations to give him grommets for his ears, for glue ear and opening up the tubes in his nose, the head banging certainly did decrease.

A3: A few years ago I couldn’t figure out why my daughter was biting her hands. I spoke to a doctor about it, and they decided to test her, and they discovered that she suffered from Raynaud’s syndrome, which affects the supply of blood to the hands and feet. She was obviously feeling tremendous pain and couldn’t tell me, so she would try and stop it by biting. This has improved since we discovered that she has the Raynaud’s and it’s getting treated.

For more information and what to do if your son/daughter is showing self-injurious behaviour, please refer to our new DVD resource: Self-Injurious Behaviour. (Order form, page 7).

Want to join the debate? Membership of our email networks is free to both parents and professionals. Application forms from www.challengingbehaviour.org.uk or email info@thecbf.org.uk

What parents say

My son dials random numbers on the phone and runs up expensive bills. The solution I found was to use BT’s service which blocks any outgoing calls where a special code has not first been entered...

My son found he enjoyed unravelling toilet rolls and stuffing the paper down the toilet – resulting in frequent toilet blockage! The solution I found was to squash the toilet roll flat as this prevents the toilet roll unravelling as quickly...

My son frequently wakes during the night and wanders the house. We are constantly worried that he will cause danger to himself – or even abscond without us knowing. The solution we used when he was younger (adapting the bottom half of the door so it can be locked to the frame and acts like a stable door, preventing him from climbing out but allowing us to check on him) is no longer any use – so what we do now when we go to bed is to set the burglar alarm...

We used to have a big problem with bed wetting, and found the best solution was to make the bed up in layers. The first layer was a terrylene covered waterproof sheet, then a plastic sheet over the top with a machine-washable continence blanket on top of this. We always had a bowl and clean pyjamas near by. If the individual wets the bed you can take off the pyjamas, sheets and continence blanket and put them into the bowl, then put clean pyjamas on and they can still get into a clean bed. More able individuals will learn to do this themselves if this routine is followed, meaning you don’t get woken in the night...

Have you found a practical solution to managing your son/daughters challenging behaviour that you could share with other parents? Do you have a problem and would like to know other families’ strategies? Use this column to share your questions and ideas...

Summer 07 Challenge 3
**Death by indifference**

In this shocking report Mencap present the stories of six people with a learning disability who have died unnecessarily. They set out why they believe there is institutional discrimination within the NHS, and why people with a learning disability get worse healthcare than non-disabled people.

One of the people featured in the report is Emma:

“Emma died of cancer on 25 July 2004, aged just 26. She had a severe learning disability, which meant that she sometimes exhibited challenging behaviour and had difficulty in communicating how she felt. The hospital delayed treating her because they said she would not co-operate with treatment and therefore could not consent to treatment.”

The Mencap report concludes:

“Professionals needing to treat people with a learning disability are often ignorant of issues around consent and capacity to the extent that the person with learning disability is often denied treatment. Doctors and nurses can sometimes wrongly believe that someone is refusing treatment. For example, someone may pull out tubes or recoil from an injection because they are frightened or in pain. But this does not necessarily mean they are refusing treatment and they would rather die. It simply means they do not understand the consequences of either having or refusing to have the treatment.”

As a result of this report the Secretary of State for Health announced an independent inquiry into the six deaths and their national implications.

The “Death by indifference” report can be downloaded from the Mencap website: www.mencap.org.uk or ordered from Mencap, 123 Golden Lane, London, EC1Y ORT. Telephone: 020 7454 0454.

Make sure that all health professionals you are in contact with are aware of the findings of this report – and are taking steps to address the issues raised.

**Prescription for Change**

We were so worn down by the time the boys were six and four that Social Services were called in. We were completely exhausted and at the point of collapse.

We were offered one evening respite a month. Our relief was immeasurable.

So we sat there in the pub. On our own for the first time in five years. Dave looked at me. I looked at him. We had nothing to say. We’d invested so much time and energy in the boys, we had nothing left for each other.

It felt sad and awkward. I was under weight, and Dave was over wrought. We seemed to have reached our lowest point.

In desperation we went to our GP. We knew we had to cope and we thought the only way to do this was with the help of anti depressants. Our GP had other ideas.

After listening attentively to our plight for over half and hour (yes, it’s patients like us that mess up surgery appointment systems - sorry!) he scribbled on his prescription pad, peeled it off and handed it to us.

‘Take up a hobby!’ it said.

It sounded trivial, considering the strait jacket we were in, but we took the well meaning advice, and spent the next week or so looking through the papers for inspiration.

‘How about golf lessons?’ I said eventually, pointing at an advertisement. We had both been good at sport. And so, on our monthly evenings of respite, we learned to play golf. The Golf club were happy to adapt our course so that we could attend once a month. Amazingly it worked.

We played golf on our one evening off, totally free from the pressures at home. Conversation became natural again. (Made a little hard, however, when we were on opposite sides of the fairway looking for lost balls!) But we were where we belonged: together and enjoying each other’s company, and other people’s company too. We had fresh air, exercise and a lot of laughter therapy.

We owe a great deal to that GP.

**Planning for the future**

“Who is going to sort everything out for my sons if I’m not here?”

“My concern is that he gets forgotten when I am no longer alive to fight his corner”

If, like these two parents who responded to our questionnaire last year, you have concerns for your son/daughter’s future, Mencap’s Wills & Trusts information service may be able to help.

The Mencap Wills & Trusts team helps people to secure future financial support in the best possible way for a loved one who has a learning disability. Some of the free services Mencap provides includes helpful guides and booklets (‘Leaving money in Trust’, ‘A guide to making your will’, ‘An easy-to-read guide to wills’), free two-hour ‘Planning for the Future’ seminars across the country, a recommended directory of specialist solicitors, and a Mencap in-house wills and trusts solicitor.

Mencap Trust Company Limited is a company that manages discretionary trusts set up for people with a learning disability. Some people choose to appoint a company rather than an individual to act as the trustee of their trust. This may be because they do not know anyone who can act as trustee, or because they do not want to place the responsibility on them. In addition, the trust company has expertise and experience in running trusts.

To find out more about any of these services call the Mencap Wills and Trusts team on 0207 696 6925, email: willsandtrusts@mencap.org.uk or visit: www.mencap.org.uk/willsandtrusts.

For details of Mencap’s free ‘planning for the future’ seminars, see page 7.
A big thank you to all those of you who have written to tell us what you think about our new DVD resource on self-injurious behaviour. Here are some of the comments received:

“Listening to the parents and seeing the home video was really helpful”

“We are very grateful for the help received. Until now we were left on our own to struggle with almost no advice or support”.

“We realised that what we are experiencing with our daughter was something unusual and that we did need help. Professionals had told us it was a phase and that we had to ignore it”

“It made me understand that intervention can be seen as a reward. I have started to think about the behaviours in a different way. The parents’ views and seeing other young people displaying made me feel as if I wasn’t on my own…”

“The explanations from the professionals were helpful. The parents voicing their concerns that parents need to be listened to and advised correctly was important.”

“Very clearly explained. Useful to have various viewpoints i.e. carers and professionals. It was very well put together, very positive and easy to watch”

“The real life examples are such a help”

To order, see page 7

At the Challenging Behaviour Foundation we receive many queries from parents about what they should do when their adult son or daughter’s placement is no longer suitable for them or is on the verge of breaking down. Often there doesn’t seem to be any service locally that can meet their needs and they may only be offered out-of-area placements hundreds of miles away from their family.

Recent government policy has emphasised equality and inclusion: people with disabilities have the same rights as anyone else to be fully included within society. However translating policy into practice has created some challenges, and it has been acknowledged that people with complex needs, including those with severe learning disabilities and challenging behaviour, have not benefited as much as they should have.

A key tool for improving the lives of people with learning disabilities is a Person Centred Plan. The new information pack from the Challenging Behaviour Foundation – Adult Services: What are the options? – complements our Transition information pack, and shows parents with an adult son/daughter how Person Centred Planning can be the key to their son or daughter’s needs being met. The pack covers the options available for adults, including housing, support, funding, education and employment, and information on developing local specialist services.

To order your copy of the new information pack, please see page 7.
The Challenging Behaviour Foundation, ten years old this year, is committed to seeing children and adults with severe learning disabilities, who are described as having challenging behaviour, having the same life opportunities as everyone else. We believe this is possible if the behaviour is properly understood and appropriately managed, and we aim to support parents and carers through education and information to enable this to happen.

But how many more families need to know about the CBF? One mother from Scotland told us: ‘I have been searching for information for seven years’. Another from the South of England said: ‘I wish I’d had this (DVD) when my son was little.’

We urgently need to reach such families.

Please consider how you can help us in this, our 10th Anniversary year, to raise our profile and to reach more families. We are a small team with big plans – and we hope that you will support us as we approach the next ten years.

Please see page 8.
Resource order form

All our resources relate to the care of individuals with severe learning disabilities who are described as having challenging behaviour.

Parents/ family carers please note: While we are happy to send our resources free of charge to parents/ unpaid carers, if you can afford to send a donation this will help us to provide free resources to other families. Thank you.

<table>
<thead>
<tr>
<th>Information sheet Health and Challenging Behaviour</th>
<th>£1.00</th>
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<tbody>
<tr>
<td>Information pack Challenging Behaviour</td>
<td>£10.00</td>
</tr>
<tr>
<td>Information pack (England only) Transition: what are the options?</td>
<td>£10.00</td>
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<tr>
<td>Information pack (England only) Adult services: what are the options?</td>
<td>£10.00</td>
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<tr>
<td>DVD A new pathway for young people with severe learning disabilities</td>
<td>£10.00</td>
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<tr>
<td>DVD Self injurious Behaviour</td>
<td>£31.50*</td>
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<tr>
<td>Video Self injurious Behaviour</td>
<td>£35.00*</td>
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<tr>
<td>DVD An Introduction to Challenging Behaviour</td>
<td>£31.50*</td>
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<tr>
<td>Video An Introduction to Challenging Behaviour</td>
<td>£35.00*</td>
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Postage & Packing

All prices include postage. For orders outside the UK please add £7.50 per item

Donation

| * Registered charities: DVDs £16.50 or videos £20. Price includes postage & packing in the UK only. |

All proceeds go towards helping families caring for individuals with severe learning disabilities and challenging behaviour. Thank you for your support

Gift Aid means we can claim back the tax on your gift (28p for every £1 you give) at no extra cost to you. If you are a UK tax payer and would like to Gift Aid your donation, please sign here:


Please indicate if you are a parent or unpaid carer. If you are a registered charity please give your charity registration number:

Name

Organisation

Address

Postcode

Your personal data may be held on computer and will be kept in accordance with the Data Protection Act 1998 under which we are registered as a data controller. This data will not be passed on to any third party without prior consent.

Please make cheques payable to the Challenging Behaviour Foundation and return to the Challenging Behaviour Foundation, c/o Friends Meeting House, Northgate, Rochester, Kent, ME1 1LS

For more information about our resources visit our website www.challengingbehaviour.org.uk

Planning for the future – free seminars for family carers

Friday 13 July, 2007 – Maidstone
Monday 16 July, 2007 – Crawley
Tuesday 17 July, 2007 – Chichester
Wednesday 18 July, 2007 – Hastings
Thursday 19 July, 2007 – Woking
Friday 20 July, 2007 – Margate
Monday 13 August, 2007 – Southampton
Tuesday 14 August, 2007 – Didcot
Wednesday 15 August, 2007 – Banbury
Thursday 16 August, 2007 – High Wycombe
Friday 17 August, 2007 – Andover
Monday 20 August, 2007 – Trowbridge

See page 4 for more information, or contact: Gina Collins, Mencap Wills and Trusts team, Freepost WD3537, London, EC1B 1AA, telephone 020 7696 6925

Have your say

Do let us know what you think of ‘Challenge’. Which are the items you found most helpful? What would you like to see in future editions? Please get in touch and help make this become YOUR newsletter.

Disclaimer

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Please support our 10th Anniversary ‘Find the Families’ appeal

YES I would like to support the work of the CBF
Please tick as appropriate:

☐ I would like to support the CBF regularly. Please send a standing order form
☐ I enclose a donation to help you to reach more families in 2007
☐ I would like to Gift Aid my donation*

* Make your gift worth more! If you are a tax payer, Gift Aid enables us to claim tax back on your gift – 28p from the Inland Revenue for every £1 you give. There is no extra cost to you.
Gift Aid declaration: I am a UK tax payer and I undertake to pay the CBF all donation I make while a UK tax payer as part of the Gift Aid scheme

Signed

Date

Name

Address

Postcode

Your personal data may be held on computer and will be kept in accordance with the Data Protection Act 1998 under which we are registered as a data controller. This data may be used by the charity for administration and fundraising purposes and will not be passed on to any third party without prior consent.

☐ I would like to join the CBF 100 Club 2007. Each share entitles me to a chance to win a monthly prize of £25. All proceeds help with CBF running costs. I enclose a cheque for £ (£12 per share)

☐ I would like to help you reach more families. Please send me brochures to distribute to families/professionals.

☐ I would like to support the CBF. Please send me information on how I can help.

☐ Please remove me from your mailing list.

Please return to:
The Challenging Behaviour Foundation, c/o Friends Meeting House, Northgate, Rochester, ME1 1LS

Thank you for your support

The CBF – how you can help

Did you know…..?

• The CBF does not charge parents for services or resources

• To keep costs down much of our work is carried out by volunteers

• If everyone reading ‘Challenge’ gave just £15 a year we would have a guaranteed income of over £25,000, which would enable us to take forward a number of important projects

• Regular giving by standing order makes your money go further by helping keep down administrative costs.

• Your support really would make a big difference to us!

Please help us to ‘Find the Families’.

Send a donation to our 10th Anniversary ‘Find the Families’ appeal, and your contribution could help us reach the families who need us. (see page 6)

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