

INFORMATION SHEET



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severe learning disabilities

Self-injurious behaviour

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Self-injurious behaviour was defined by Murphy and Wilson (1985, p. 15) as:

'Any behaviour, initiated by the individual, which directly results in physical harm to that individual. Physical harm (includes) bruising, lacerations, bleeding, bone fractures and breakages, and other tissue damage.'

This definition was used in a large UK research project (for details see below). It focuses on the tissue damage which is, after all, implicit in the term 'self-injury'. However, there have been some debates about the limitations of this definition. For example, there have been discussions about whether behaviours like self-induced vomiting (which can be life-threatening) and trichillomania (pulling out your own hair), should be included under 'self-injury' since both may involve tissue loss, if not direct tissue damage.

It has also been argued that behaviours of the same topography (form) as a self-injurious behaviour (such as light head tapping, that is not currently producing tissue damage) should be included as self-injury. Behaviours like these, that are not producing injuries, are normally referred to as stereotypies (repetitive apparently purposeless movements). All researchers and clinicians agree there is a close connection between these two types of behaviour (see also below).

How common is SIB?

Early studies of self-injury surveyed hospital populations only; community-based studies began to appear in the 1980s (see for example, Oliver et al., 1987 and Murphy et al, 1993). From all these studies, it seems that:

- around 8-15% of people living in hospitals for people with learning disabilities show self-injury
- about 3% of adults with learning disabilities living in the community show self-injury
- about 3-12% of children with learning disabilities, living in the community, show self-injury, the highest rates being for teenagers
- some people live in the community despite extremely severe self-injury (for example, Oliver et al. found that half of the children and adults in their survey who had very severe self injury and wore protective devices, were living in the community).

Some individual characteristics seem to be associated with an increased risk of having self injurious behaviour:

- sensory deficits

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- poor expressive language
 - autism
 - severe or profound disabilities
 - poor mobility
-
- specific syndromes, such as Lesch-Nyhan syndrome, Smith-Magenis syndrome, Prader-Willi syndrome, Tourette's syndrome, De Lange syndrome

Lots of children with learning disabilities have some of these characteristics; not all of them show self-injury. The only factor in the list that is sufficient on its own to produce self-injury is Lesch-Nyhan syndrome. This syndrome is very rare though, so professionals are more likely to meet individuals with serious self-injury who have the general risk factors (like autism, poor expressive language and so on) than individuals with Lesch-Nyhan syndrome (for example, Oliver et al., 1987, found only 4 people with Lesch-Nyhan syndrome out of the 596 adults and children who showed self-injury in their survey of South East Thames Health Region).

How does SIB start?

Very little is known about how self-injury starts. What is known is that it sometimes begins in very young children with severe or profound learning disabilities and/or autism. A research project in London and the South East followed about 20 young children with early stage self-injury for 2 years (Murphy et al., 1999). It was found that, for many children, self-injury seemed to begin very insidiously, as a stereotypy, causing no tissue damage at all. Self-injury in some of these children got worse over the following years; in others it disappeared. It seemed that one of the important factors in whether the self-injury increased or decreased was how teachers and parents reacted to the behaviour (i.e. whether they 'shaped it up', without meaning to). A further follow-up of these children is now under way.

For the small number of children with Lesch-Nyhan syndrome, in the research project, self-injury seemed to begin rather differently, with sudden intense biting that could produce bleeding very quickly. For all the children with Lesch Nyhan syndrome, the rates of self-injury increased, over the two years of the study.

How chronic is SIB?

It is difficult to be sure how chronic self-injury is. There are published reports of individuals who have been self-injuring for many years. But these may be unusual people, with very extreme self-injury, who have been referred as far as a teaching hospital or a university affiliated programme. What about all the others with less extreme self-injury?

In one large survey from the USA, it was concluded that self-injury did not seem to be chronic because 90% of the people with learning disabilities reported to show self-injury in one year were reported as not showing it the following year (Schroeder et al. 1978). However, Schroeder later followed up 52 of the individuals in his cohort with the most severe self-injury and found that they showed only temporary improvements in SIB, so that they were still self-injuring eight years later (Schroeder et al., 1986). Other studies have tended to find the same, especially for people with severe self-injury (for example,

the SE Thames study found people with severe self-injury had been self-injuring for an average of 14 years, Murphy et al., 1993).

It has to be concluded that:

- *severe* self-injury seems to be very chronic
- very little is known about whether less serious self-injury comes and goes (there is some evidence that it gets worse in teenage years, gets worse with physical illness and can get worse under certain environmental conditions).

What kinds of treatments help to reduce self-injury?

There have been lots of reports of successful treatment for people with severe self-injury, mostly as a result of behavioural treatment (see for example, AABT Task Force Report, 1982; Murphy and Wilson, 1985; Emerson, 1992; Oliver, 1995 for reviews). Medication, in contrast, appears not to work very well, with one exception. There are also methods of prevention which may help.

What is behavioural treatment?

Behavioural treatment, which is usually provided by psychologists or behavioural specialists, works well for learnt behaviours. The rationale is that:

- Children (or adults) with severe learning disabilities and self-injury have often learnt to 'use' their self-injury to communicate with others.
- They are not necessarily doing this deliberately
- They may just have discovered by accident that if, for example, they hit their head, then their mother or carer will come over and give them a drink or a cuddle
- The 'messages' that SIB often seems to convey include 'come here', 'go away', 'I want a drink' (or food or a toy), 'I'm bored' or 'I need help'.
- Behavioural treatment involves working out what 'message' the person is trying to convey and then teaching them a better way to 'say' it.

This is harder than it sounds because it is difficult to work out what people are trying to communicate through their self-injury. Sometimes people use their self-injury to mean different things at different times. It is also quite hard to teach better ways to 'say' things, when someone has very few language skills. Psychologists and behaviour specialists have tried teaching people to use new words or phrases (if they can speak) or new signs (like Makaton) or picture cards to replace the SIB and show their teachers or carers what it is they want. This process of teaching better ways to communicate is called functional communication training or FCT (because it involves teaching communication skills that match the function of the self-injury) and it is described well in Carr et al., 1994 and in Durand, 1990. This kind of language training, FCT, has to be combined with new ways of responding to the self-injury as well: essentially the self-injury must no longer be reacted to as though it were a 'message'.

Increasingly, functional communication training (FCT) is the treatment of choice for self-injurious behaviour. The acquisition of communicative skills, through FCT, should allow an individual to make a variety of requests, so that the person acquires more control over his/her social environment. One of the most difficult issues, however, has been how to provide such communicative skills for the most disabled individuals and this has required some ingenuity, such as the use of audiotape machines with pre-recorded messages (Durand and Kishi, 1987).

What kind of medication helps?

There is only one type of medication that has been consistently found to help in reducing self-injury: naloxone or naltrexone. It is a difficult kind of medication to use and has to be employed under very careful medical and psychological supervision.

This medication works in an unusual way. It was always a puzzle that self-injurious behaviour, especially in people who have shown SIB for years, sometimes did not seem to cause pain, at least in some individuals. This led to the suggestion that, in some cases, repeated self-injury produced an increase in endogenous opiates or endorphins (internal morphine-like substances). It was suggested that this either had the effect of deadening the pain from SIB or of producing an addictive 'high' following self-injurious responses. In either case, it was suggested that the blocking of endogenous opiates by medication like naloxone or naltrexone would have the effect of reducing self-injury, at least while the medication was being taken. This does seem to be the case, though not everyone with SIB seems to respond to this treatment. In one of the largest trials, Thompson et al. (1994) suggested that the effect of the naltrexone might depend in part on the topography of the SIB and site of injury.

Do behavioural treatments and medication ever get combined?

It is perfectly possible, of course, that an individual who has been self-injuring for many years may have developed high endorphin levels as well as clear functions (or 'messages') for his/her self-injury. It might be predicted that for these people a combination of functional communication training and naltrexone might be the most effective treatment and a recent study by Symons et al. has suggested that this is indeed the case for some people (Symons et al., 1998).

What about protective devices?

When someone's self-injury is very severe, people often begin to use protective devices to try to prevent the person from injuring themselves. The kinds of protective devices used include padding (of bed sides or wheelchairs), helmets, gloves and arm splints. Such devices are best used as short term measures: they are usually unhelpful in the long term, as people often get very dependent on them and sometimes the devices restrict their movement and their lives generally. Sometimes these devices are necessary in the longer term, though – mainly for boys with Lesch Nyhan syndrome.

What about early intervention?

Early intervention programmes, in the pre-school years, have usually focused on helping children to gain skills, rather than reducing challenging behaviours, like self-injury.

However, one of the few early intervention programmes that did focus on reducing challenging behaviours, was that of Lovaas (1987). He maintained that very early, very intensive behavioural training for children with autism could return the children to near-normality (Lovaas, 1987; McEachin et al., 1993). Not everyone has accepted Lovaas' claims and there remains some doubt about whether all children with autism would respond as well as this. To some extent these debates have involved the issue of whether some difficulties are biologically based or 'hard-wired' and therefore difficult or impossible to alter.

Nevertheless, for children with severe or profound learning disabilities who are just beginning to self-injure at very low rates and low intensity, it is possible that early intervention with behavioural methods might be very effective, especially where no biological basis for their self-injury is identified.

What can you do?

For parents and teachers, there are probably three really important tasks when someone is developing self-injury:

- Teach communication skills, even if this involves unusual methods of communication
- Ensure the person is safe but, as far as possible, do not react to the self-injury as though it were a 'message'
- Seek specialist advice from the local clinical psychologist or behavioural specialist as soon as possible

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