TIP SHEET: A guide for parents, carers and professionals LONG VERSION

Why Does My Child Hurt Themselves?

Helping Children with an Intellectual Disability and Autism Manage their Self-Injurious Behaviour

WHAT IS SELF-INJURY?

The term self-injury is commonly used in disability to describe behaviour that results in a person causing physical harm to themselves. The injury usually happens when the young person is trying to communicate a message or need.

Sometimes, self-injurious behaviour can start as repetitive behaviour used by the child or young person to make themselves feel better (to sooth, calm, or remain alert). These behaviours can be shaped and rewarded by the responses of others. The young person can learn that these behaviours are useful in having their needs met.

Diagnoses of intellectual disability and autism make it more likely that a child or young person will self-injure. The more severe the intellectual disability, the more likely it is that they will self-injure.

Most young people with intellectual disability and autism find organising, planning, problem-solving, remembering, and controlling emotions hard. This can make resisting the urge to self-injure difficult, especially when they can't communicate their needs effectively. Problems coping with everyday challenges can also make it hard to stop once they have started.



WHAT DOES SELF-INJURY LOOK LIKE?

Some children and young people may use more than one way of hurting themselves. How often the behaviour occurs, and how intense or harmful it is, also varies from mild and infrequent, to severe and chronic.

Self-injurious behaviours include:

- biting themselves, e.g. biting hands or fore arms
- striking their own body with hands or fists, e.g. slapping their face, hitting their temple with a closed fist
- striking their own body with an object
- hitting their own body against an object, e.g. banging their head on the floor or wall
- scratching, skin picking or pinching
- hair-pulling
- eye poking and gouging
- eating inedible objects.

WHY DOES MY CHILD HURT THEMSELVES?

Considering **why** your child or young person might be hurting themselves will help you choose the best way to respond. Sometimes, different behaviours mean different things at different times.

Some reasons for self-injury include:

- physical health issues e.g. pain, ear infections, reaction to medication, constipation, poor sleep (being tired makes coping with challenges more difficult)
- genetic pre-disposition some genetically determined syndromes can make a person diagnostically vulnerable (more likely) to self injure, e.g. Smith Magenis Syndrome, Cornelia de Lange Syndrome, Fragile X, Lesch-Nyhan Syndrome and Rett Syndrome

- sensory sensitivities self-injury can be used by a child to increase their level of arousal /alertness (e.g. touch, movement, sound) or to offset overwhelming sensory input.
- eliciting care from others self-injury can draw others to the child for assistance, for company and interaction, or to make them feel safe.
- functional communication difficulties a child's inability to communicate their wants and needs can lead to frustration and self-injury; also, difficulties understanding the messages of others can lead to confusion, apprehension and self-injury. Wants and needs can include tangible things such as an object, food or an activity.
- escaping / avoiding activities -some children learn that self-injury can be used to avoid a task or activity, to leave a place, or to be left alone. If the response to self-injury is finishing an activity, self-injury can become an effective way of avoiding participation.
- emotional state low mood is often linked to selfinjury. Self-injury can also be an attempt to release tension or relieve anxiety. Coping with challenging life events and transitions can create stress and trigger self-injury.

Some children and young people with intellectual disability and autism may have imbalances of chemicals in the brain that regulate thinking, mood, and their response to pain. It may be made worse by ADHD, anxiety, depression or mood instability and is facilitated by stereotypic repetitiveness.

When self-injury occurs repeatedly, the body can produce increased amounts of endorphins. These are hormones that block or reduce physical pain and stress, and create a general feeling of well-being. Self-injury may be maintained by access to these 'feel good' chemicals.

HOW CAN I HELP?

Self-injury can have a high impact on the child or young person, their family, paid carers and teaching staff. Watching them hurt themselves can be both distressing and exhausting. Concerns about wound care, and the risk of lasting damage to head, eyes, and other parts of the body, puts pressure on supports to understand and respond in a helpful way.

Seek help early. Timely assessment and intervention may prevent self-injury from becoming habitual.

First Steps:

 Organise a review of your child or young person's health – rule out or treat any underlying conditions causing pain or discomfort.



 Systematically explore why the child or young person might be self-injuring. A Psychologist or Behaviour Support Practitioner can undertake a Functional Behaviour Assessment to evaluate how the self-injurious behaviour is useful to the child or young person, and how their behavioural goals might be met in other ways.

The child or young person's health team, Speech Pathologist, Occupational Therapist and teaching team will be well-placed to contribute to this assessment, alongside family members.

Following a comprehensive assessment, a Behaviour Support Plan is usually developed and is likely to include strategies focused on reducing the need for self-injury, such as:

schedules and routines that provide certainty and predictability. Predictability reduces confusion and apprehension, and provides comfort

schedules and routines that contain preferred activities, and opportunities for social connection, being physically active, learning skills and making choices

routines to prevent difficulties, e.g. 'getting to bed' (wind down) routines to promote sleep and reduce daytime fatigue

nteraction strategies to enhance sharing information with the child or young person

teaching strategies that provide the child or young person with ways to sooth and calm themselves when upset, or remain alert when feeling sluggish, e.g. relaxation techniques, deep breathing, physical activity teaching adaptive skills that enable the child or young person to meet their needs more independently

anticipation of sensory challenges and the development of strategies to help your child manage them, e.g. taking noise-cancelling headphones if going somewhere loud

response strategies that describe how everyone will respond (consistently) when the self-injury occurs

reward of positive behaviours

reassurance, support and reduced demands to relieve anxiety and worry

calm and attuned caregiving without over responsiveness to the self-injury.

CAN MEDICATION HELP?

Every child and young person is different. For some, psychoactive medication can be helpful, particularly when used in combination with Positive Behaviour Support. Most people recommend starting with a good quality functional behaviour assessment followed by positive behaviour support. Some medications may not decrease self-injury directly, but might facilitate the impact of other positive behaviour interventions.

Medication that addresses pain as a potential trigger of self-injury may also be of benefit. Keeping track of any changes to behaviour that follow giving pain relief can be useful in assessing the cause of the behaviour.

Speak to your GP, Paediatrician or Paediatric Psychiatrist about whether medication might help your child or young person.

CAN PROTECTIVE EQUIPMENT HELP?

Keeping your child or young person safe is a key priority. Some families decide that the intensity and/ or chronic nature of the self-injury necessitate more support. Sometimes, restraints or protective headgear are used to minimise or prevent physical harm. These devices are usually prescribed by occupational therapists, in collaboration with other professionals. Restraints and protective devices include helmets, clothing such as gloves and sleeves, splints, and

clothing such as gloves and sleeves, splints, and padding. The decision to use them should be made in consultation with the young person's treating professionals, and consider factors such as:

- Restraints and protective devices do not address the cause of the behaviour, so are best used short term. They may provide some benefit by reducing self-injury or preventing actual harm, but they have limited potential to create behavioural change.
- It is possible that the child or young person will find other ways to self-injure while wearing the protection.
- The child or young person is unlikely to develop alternate strategies or skills while using the device.
- Protective devices usually restrict a child or young person's movement and can limit participation.
- Protective devices may be useful in enabling safe 'self-restraint' for children and young people who want to stop their self-injury but struggle to manage.
- Current legislation requires some services seek authorisation to use restraints and protective devices. National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018

WHEN & WHERE TO GET MORE HELP:

Additional to the professionals described above, it is important to think about services to support the family. Opportunities to explore emotions and take a break can be invaluable.

Consider sourcing a counsellor for yourself and /or other family members experiencing stress. Respite for the family may also allow rest and recovery. If it feels difficult to trust a service with the safety of a child who self-injures, invest in building a relationship with your support network. Inquire about the possibility of the Behaviour Support Practitioner or Psychologist delivering training to the respite service.

If at any time you are concerned, seek help and advice. In an emergency, call 000.

If you have any feedback on this tip sheet please fill in our <u>feedback form</u>. You can find readings, resources and links related to this topic on our <u>webpage</u>.

If you are still concerned, contact your GP or Paediatrician about services that might be helpful.



