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Understanding and managing pica

James Frankish was autistic and had a learning disability and severe <u>pica</u> (the <u>eating of non-foods</u>). In his family's words, caring for James was a great privilege but also a challenge. His family went to great lengths to keep him safe, however he was very fast, fit and active and always appeared to know when his carers were distracted or had relaxed. This was often when he would grab something and run off with it. As a result, despite the best efforts of those around him, it proved impossible to completely stop James from engaging in pica.

James's pica was recognised as being severe. The reason for this was the huge variety of items he would eat, such as conifer leaves and other plant material, his long history of engaging in pica and his compulsion to obtain his preferred items.

Very tragically, his pica behaviour was a factor in his untimely death at the age of 21. Such severe pica is relatively rare but the consequences for the person who engages in it and their family and friends can be devastating, as it was for James and his family, whose tragic story we told in <u>our corresponding article on this subject</u>.

In this second article we will concentrate on what is known about interventions or treatments for pica, particularly for autistic people. It is written again in collaboration with James' family and aims to bring together evidence from research, clinical practice and strategies that families develop themselves.

By doing so, we hope to continue to highlight the dangers of pica behaviour and to provide support to those currently managing what is still a poorly understood, socially stigmatising and potentially lethal condition.

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Diagnosis of pica

Getting a diagnosis of pica can be the first step towards effective management, not least because early intervention may prevent harm and the need for more complex treatments further down the line. Health professionals who can diagnose pica include paediatricians, gastroenterologists, psychiatrists and/or clinical psychologists.

The Diagnostic Criteria for Pica from DSM 5 (American Psychiatric Association, 2013) states that pica is:

Persistent eating of non-nutritive substances for a period of at least 1 month. The eating of non-nutritive substances is inappropriate to the developmental level of the individual. The eating behaviour is not part of a culturally supported or socially normative practice. If occurring in the presence of another mental disorder (e.g. autistic spectrum disorder) or during a medical condition (e.g. pregnancy) it is severe enough to warrant independent clinical attention.

Good assessment of a person's pica is also very important, although this can be a long and complex process. Assessment may include questionnaires and/or observation of the frequency of pica, what is being eaten and what led up to the pica episode.

We do not, as yet, know why people engage in pica. Some possible reasons include:

- lack of awareness of what is, and is not, a food
- to gain attention or avoid a demand
- to relieve anxiety or distress
- for social attention
- to obtain or escape something
- a lack of adequate nutrition
- for sensory feedback.

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A detailed assessment of James's pica never took place. This appeared to be due, in part, to a lack of knowledge about pica in professionals involved in his care – a common experience. There were also no pica-specific assessment measures available during James's lifetime. Very positively, although sadly too late for James to benefit, there is at least one such measure now in development (Bryant-Waugh et al, 2018).

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However, it was clear that James's family understood his pica and that for him it appeared to be a sensory need and compulsion that made him happy and could calm him in times of anxiety. Clinical experience with autistic people suggests that sensory feedback, such as the taste and texture gained from the pica items, appears to be an important factor as does the compulsive quality of the behaviour itself. In addition, that pica often appears to increase when the person is anxious or is 'dysregulated' (unbalanced) from a sensory point of view. In these cases, pica may serve, in part, as a self-soothing behaviour.

Support for pica

There are currently no evidence-based treatments for pica and research into this area, particularly with autistic people, is limited and inconclusive.

Historically, interventions have focused on a variety of methods to reduce or eliminate pica. These have included:

- nutritional supplementation
- approaches such as redirecting encouraging the person to throw the item away instead
- restricting access to harmful pica items
- promoting self-soothing behaviour
- making the environment 'pica-safe'
- replacing pica items with similar, safe alternatives (Matson et al, 2013).

It remains unclear which of these might be the most effective, although behavioural based interventions have been given the most attention in the literature. Given that pica is likely to involve a number of factors, a combination of approaches is most likely needed (Matson et al, 2011).

There are also clinical or practice-based interventions that appear to reduce pica. These need to be tailored to each person and come from a thorough understanding of the behaviour. In general, a multi-disciplinary approach, in other words one that includes the input of a variety of different health professionals working together, is likely to be the most beneficial. Information about pica should be included on medical records, care plans and education health and care plans (EHCP). Information should also transfer with the person, for example, from school to residential care/college (Stiegler, 2005).

Advice from James' parents

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James's family used a combination of approaches to manage his pica. Some of their very inventive strategies are outlined below. In particular, they found that reducing James's stress by distracting him or helping him self-regulate using 'twiddlers' (fiddle objects made of pipe cleaners, bottle tops and beads) would help to sometimes reduce his pica.

They also carefully managed his environment by banning or substituting certain items, for example offering Twiglets as a substitute for eating wood. Parts of the garden were fenced off to prevent James from eating inedible plants.

Some tips and advice from James parents on managing pica at home:

- 1. Use distraction at the supermarket by giving them a punnet of vegetables (or alternative) to eat. This can prevent them taking other items from the shelves or other people's trolleys. The staff will get used to you passing empty packets through the checkout!
- 2. Place cups of vegetables/salad in the garden to reduce plant eating.
- 3. Learn which plants are toxic and plan routes when out to avoid these.
- 4. Avoid using chipped bark for ground cover outside. Small size pebbles (which pass through the bowel more easily), decking or paving is better.
- 5. Record pica items and watch for them in the individual's stools.
- 6. Ensure your house has a fuse box with a Residual Current Device (RCD) breaker. Use additional RCD breakers in areas where cables can be nibbled.
- 7. Keep items with small rubber parts for example thermostats, alarms, remote control out of the way.

Management of pica

The number one priority in the management of pica is to keep the person safe. This includes monitoring for:

- dangerous pica items which may cause an immediate risk of serious harm or death such as choking, poisoning or gut perforation
- items that may cause long-term and chronic ill health, such as infections and blockages in the digestive system.

For autistic people who may not display outward signs of ill-health or pain, it is crucial that they have access to regular health checks from their general

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practitioner and/or medical specialist, such as blood tests, scans and physical examinations.

As far as possible, preventing someone from gaining access to dangerous pica items is the most effective way of ensuring safety. However, evidence from James's family and others indicates that removing a pica item or preventing access can lead to an increased level of stress and anxiety that intensifies the drive to obtain it (Sturmey & Williams, 2016). As a result, managing anxiety by distracting the person into other, meaningful activities instead of pica can help. Indeed, any strategy that calms and lowers anxiety could be beneficial.

An assessment of person's sensory functioning can help with understanding what tastes and textures are likely to be the most preferred. In addition, interventions such as a 'Sensory Diet', which helps to provide the sensory input a person needs, may lower stress and may also be able to reduce engagement in pica. Providing a 'pica-box' of safe alternatives to chew/bite or eat, such as foods of different tastes and textures and/or chewy aids can also help.

Recommended pica strategies

For parents/carers:

- 1. Keep a look out for potentially dangerous pica items.
- 2. Tell others (school, GP, health professionals) about pica.
- 3. Request support, for example from learning disability/autism or mental health services.
- 4. Provide safe alternatives to chew/bite and eat.
- 5. Distract away from pica and increase engagement in other activities.

For professionals:

- 1. Work together to manage risk and share information.
- 2. Provide access to regular physical health checks.
- 3. Provide services to assess and diagnose pica.
- 4. Include information about pica in medical records, care plans and education and health care plans (EHCPs).
- 5. Seek additional training/resources on pica.

We have written these articles to tell James's story in the hope that what happened to him will never happen to anyone else. We also hope that the ideas

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we have presented will help those currently caring for or working with people like James.

His tragic story also highlights the lack of available guidelines, advice and support for the management of pica. As a result it now remains imperative that this gap in knowledge, particularly around pica in autistic people, is addressed in order to keep everyone safe

Dedicated to the memory of James Frankish (1994-2016) and written with heartfelt thanks to his family.

Further reading

Challenging Behaviour Foundation

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