

Handout 1.1: Scenario for professionals: ice-breaking activity

Desensitisation role play scenarios

Scenario 1

Service user

You are a service user who has learning disabilities and you frequently display repetitive behaviours such as twirling and spinning. Throughout the assessment, every 10-20 seconds, either stand up and spin around on the spot before sitting down again or stand up and walk in a circle around the chair and sit down again.

Nurse

You are running a very busy clinic to monitor people's blood pressure. You have had a very busy morning with lots of patients and you have a lot more patients to see. You do not have much time allocated for each individual. You need to get each patient in and out quickly. You do not have time for patients who do not co-operate and find yourself losing your patience quickly, talking in a blunt, short manner.

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Scenario 2

Service user

You are a service user with moderate learning disabilities and you present as a very excitable person, particularly when you are nervous. Throughout the assessment you put your face close to the nurse's, laughing and giggling. You become very excitable pulling the tube on the blood pressure machine and pushing the buttons whilst the nurse is attempting to take your blood pressure.

Nurse

As the nurse you need to take the individual's blood pressure during the assessment. Ensure that you communicate effectively with the service user, providing reassurance and if necessary, distraction techniques, to ensure you can complete the procedure effectively.

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Scenario 3

Service user

You are a service user with mild learning disabilities. You have a good understanding of the need for health monitoring however you experience high levels of anxiety around any medical intervention. This causes you to become very distressed and upset, which in the past has led to you suffering from panic attacks. At the start of the assessment you are happy to have your blood pressure taken but you tell the nurse you feel a little anxious. Throughout the assessment you show signs of increased anxiety, fidgeting, looking around nervously and as the assessment progresses your anxiety and distress increases; you become tearful and worried about what is happening. You start to show signs of a panic attack, you feel very hot and your heart is racing, repeatedly tell the nurse that this is how you are feeling.

Nurse

As the nurse you need to take the patient's temperature and blood pressure which you think are both very straightforward procedures. You know people can be anxious about such procedures but you think this is silly as it is not like they are having a blood test or major surgery, is it?

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Scenario 4

Service user

You are a service user with learning disabilities and severe autism. You display self-soothing behaviour; rocking backwards and forwards whilst vocalising (humming) continually. You have a history of becoming very anxious during any type of intervention. At the start of the assessment, rock backwards and forwards slowly, making 'happy' sounding vocalisations (humming). As the assessment continues, increase the intensity of your rocking and make 'unhappy' vocalisations e.g. grunting.

Nurse

As the nurse you need to take the individual's temperature using the tympanic machine. In the past, when working with individuals with learning disabilities, you have found communicating effectively, providing reassurance and positive reinforcement (giving praise) has helped reduce the individual's anxiety. Use these techniques whilst completing this assessment.

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Scenario 5

Service user

You are a service user with severe and profound learning disabilities; you have cerebral palsy and are blind. (Please wear the blindfold provided.) You suffer with joint contractures, particularly in your arms, causing your arms to be bent at the elbow and tight against your chest. You have very limited range of movements in your arms. You like people to talk you through what is happening and tell you when they are going to touch you as you are very sensitive to touch and sudden movements frighten you. You will cry out if touched suddenly or do not know what is happening.

Nurse

You need to put a tourniquet on the patient's arm in preparation for a blood test; you do not have much experience of working with people with learning disabilities. As far as you are concerned there is not much point talking to them as they will not understand what you are saying anyway and you just want to get finished because it is lunchtime and you are hungry.

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Scenario 6

Service user

You are a service user with severe learning disabilities; you do not verbally communicate and can present challenging and self-injurious behaviour. Every 10 seconds or so throughout the examination, lightly slap the side of your face or head, kick the legs of your chair or stamp your feet. As the assessment continues increase the intensity and frequency of these actions.

Nurse

As a nurse you do not have much experience with individuals with learning disabilities; the only time you have come into contact with patients with learning disabilities was on a visit to a secure unit. The patients there were quite violent and they scared you a little. You need to take the patient's temperature using the tympanic thermometer and listen to the heartbeat using the stethoscope.

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Scenario 7

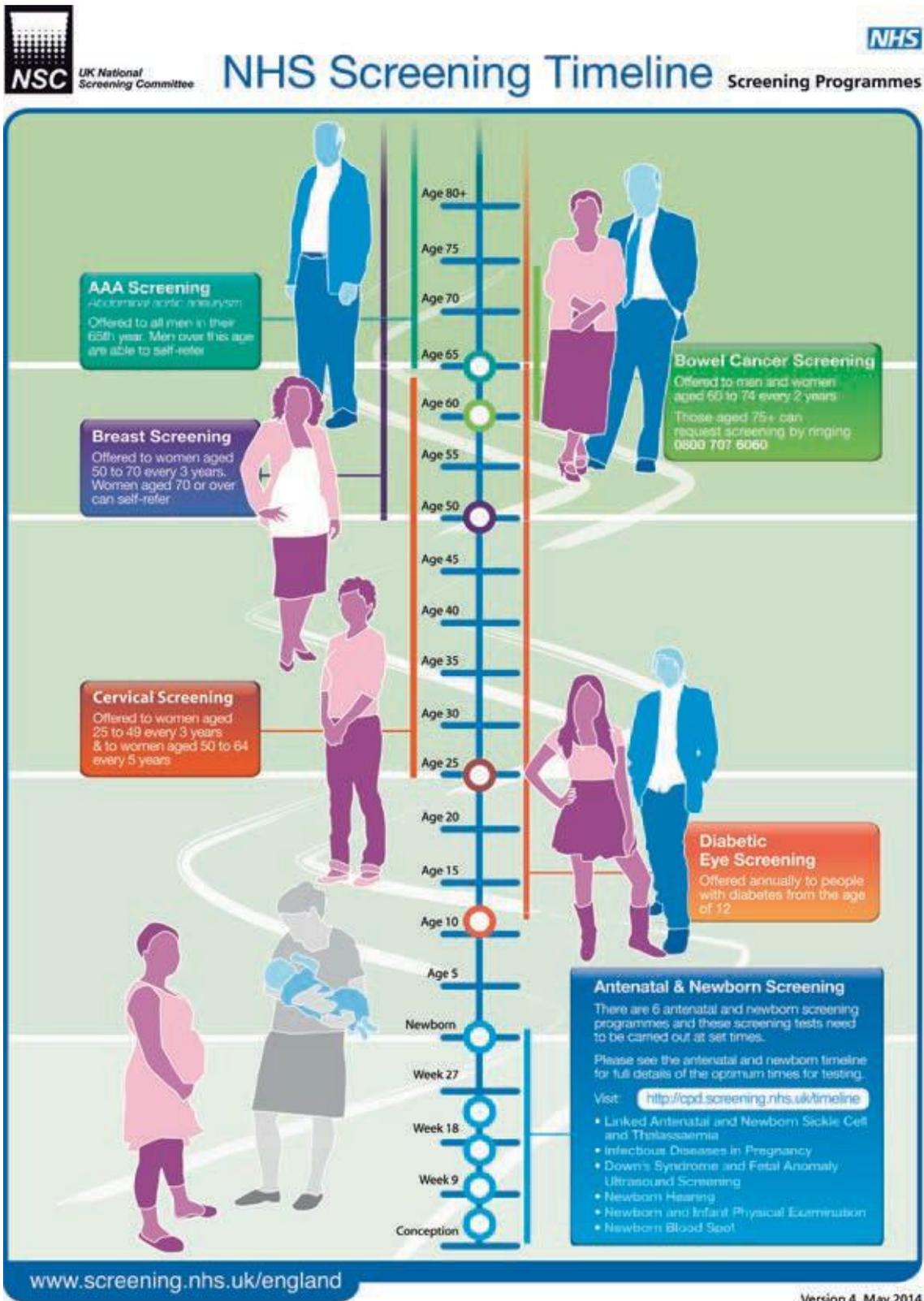
Service user

You are a service user with mild/moderate learning disabilities; you have good expressive verbal communication skills but your receptive skills are quite poor. It can sometimes appear that you have a better understanding of information than you actually do. You enjoy watching programmes like 'Casualty' and 'Doctors' and are really interested in all things medical. During your assessment ask questions about what the nurse is doing and why. If the nurse uses language you don't understand i.e. 'systolic reading', ask what she means. When the nurse takes your blood pressure and the cuff becomes tight say, 'Ouch that feels really tight. You did not tell me that would get tight'.

Nurse

As a nurse student you have not had much experience of talking to people with learning disabilities and your patient is really chatty, wanting to know all about what you are doing. You have just completed your practical examination in measuring vital signs and want to show off your knowledge of how monitoring blood pressure works, as your mentor is watching you throughout this assessment. You tell your patient all about how blood pressure is measuring the pressure of blood against the walls of your blood vessels, that the systolic reading measures the blood pressure when the heart is beating and the diastolic reading measures the blood pressure when the heart is relaxed. You are much more concerned with telling them this, than telling them what is actually happening in the assessment.

Handout 1.2: NHS timeline



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Handout 1.3: Treatments and helpful strategies to reduce anxiety and phobias

Systematic desensitisation

This form of therapy aims to help people overcome phobias and things that make people feel anxious. Desensitisation is when anxiety is reduced by gradually getting used to the object or situation which causes fear. For example, a person with learning disabilities who has a fear of visiting their doctor/GP could become desensitised to the visits in stages. Perhaps the first stage could be meeting the doctor/GP the first few times in their own home rather than the surgery. This gives the person a chance to build trust and a positive relationship with their doctor/GP. That way they will feel more comfortable meeting them outside of their home. The second stage could be visiting the surgery without having the health check so the person with learning disabilities will become used to the environment there. The third stage could be visiting the surgery and the doctor; seeing the equipment that will be used, perhaps touching it and facilitating the person with learning disabilities to use it on other people. Hopefully the person will eventually be desensitised enough to have their health screening and the phobia would be reduced or gone altogether.

Role play

Role playing can be a useful method to support someone to overcome anxiety or phobias because it is almost like exposure to the fear. If someone with learning disabilities had a fear of needles and they needed to have a blood test then role play techniques could be used to allow the person to use similar and safe equipment on themselves or other people. In a way it is aiming to turn that anxiety into a positive experience. Role playing can also give the person a better understanding of what the equipment is for and how the procedure is safe.

Relaxation

There are a number of different relaxation techniques which can be used to help someone with learning disabilities feel calm and relaxed. It is important to remember that while taking part in the relaxation techniques it is best to be sat down comfortably, either on a soft chair or a bean bag.

Progressive muscle relaxation (PMR)

PMR is when someone tenses the muscles either of their entire body or of a specific muscle group for a couple of seconds and then gently relaxes them again. If participants would like further information there is a PMR in the resource section of this pack.

Handout 1.3: Treatments and helpful strategies to reduce anxiety and phobias contd.

PMR was used with individuals during the desensitisation pilot group run by the West Kent nurses. This had a positive effect for certain individuals as part of the desensitisation process.

Focused breathing

Focused breathing is as simple as breathing in slowly through the nose for three seconds and then breathing out through your mouth for three seconds.

Maskey *et al* (2014) evaluated a unique treatment that involved a combination of exposure, CBT, and breathing exercises in order to help children with autism spectrum disorders overcome their anxiety and phobia. Nine children were involved and eight of them showed improvement, four of whom had completely overcome the fear.

Read more here: http://www.scopeaust.org.au/wp-content/uploads/2015/04/relaxation_and_disability.pdf

Both PMR and focused breathing should be repeated until the individual feels calm and relaxed. It is useful to remember that the environment can influence whether or not a person can relax. If someone is in a noisy area or a lot is going on, that person may be unable to relax. If the environment is calm and peaceful then a person with learning disabilities may be less likely to become distressed.

Sounds and music

Sound and music can assist people to relax, for example some soothing, calm music that the individual enjoys or some peaceful nature sounds. What is used depends entirely on the individual's preference.

Although there is not a lot of evidence supporting these techniques specifically for someone with learning disabilities, there is plenty of evidence of it working for people without.

Breathing exercises, role play and bespoke relaxation programmes were the most practical and useful strategies for the individuals with a learning disability within the pilot project.

Mindfulness

Mindfulness is about experiencing the world that is firmly in the 'here and now'. It offers a way of freeing oneself from automatic and unhelpful ways of thinking and responding. The Free Mindfulness Project website has a large range of guided meditation exercises that are free to download. Mindfulness practices are not new, and certain aspects, such as yoga and meditation, have been around for thousands of years.

Handout 1.3: Treatments and helpful strategies to reduce anxiety and phobias contd.

Medication

There are a variety of medications that can be used to treat anxiety; these are known as benzodiazepines ('benzos'). These are a group of medications that can act as a sedative, to treat sleeping problems and reduce anxiety.

For people with a learning disability the Mental Capacity Act (2005) must be adhered to. This pack has a section on mental capacity which can guide you further through the consent/best interest process (Part 2, Session 11).

If a person suffers from anxiety and fear from something specific like visiting the GP or a blood test, then they may need pro re nata (PRN, or 'as needed') medication. This medication could be a form of sedation so the person can get through the situation which is causing them anxiety or fear more easily, and with less distress.

It is always preferable to seek other options to reduce anxiety before considering medication. These may include relaxation, mindfulness, progressive muscle relaxation, breathing exercises, healthy eating and exercise. All these options can be used alongside the desensitisation process. There are examples of this within the case studies used in this training pack.

Within our pilot project there are examples of when medication was used to reduce anxiety prior to health screening for certain individuals. Other methods had not been successful for these individuals and this was clearly evidenced. This was led by the GP working with family, carers and other clinicians where appropriate, and following the Mental Capacity Act. For these individuals medication was used as part of the desensitisation process to enable them to successfully have their health screening e.g. a blood test. This was regularly reviewed with a view to phasing out the need for medication once the person was less anxious and had become familiar with the whole process, including the final stages. Two individuals required medication on one occasion only and have not needed this for future blood tests.

If medication is prescribed to support the desensitisation process the dose could be reduced gradually so the person becomes less reliant on sedation after each experience. Eventually the medication may not be needed because the person is fully aware of the process, knows what to expect and is no longer fearful/anxious after the reoccurring exposure.

Please refer to NICE clinical guidelines *Autism Spectrum Disorder in Adults: Diagnosis and management* (2016) when supporting people with autistic spectrum conditions regarding anxiety and prescribing medication.

These guidelines include the following:

'When discussing and deciding on care and interventions with adults with autism, take into account the:

- *increased propensity for elevated anxiety about decision-making in people with autism*

Handout 1.3: Treatments and helpful strategies to reduce anxiety and phobias contd.

- *greater risk of altered sensitivity and unpredictable responses to medication*
- *When deciding on options for pharmacological interventions for challenging behaviour or coexisting mental disorders in adults with autism:*
- *be aware of the potential for greater sensitivity to side effects and idiosyncratic responses in people with autism **and***
- *consider starting with a low dose.'*

(NICE, 2016)

Nadeau *et al* (2011) looked at the information on the efficacy of pharmacological and psychosocial approaches for treating anxiety and repetitive behaviours in children, adolescents and adults with autism spectrum conditions. They specifically evaluated evidence for the use of cognitive behavioural therapy and selective serotonin-reuptake inhibitors.

Kitt *et al* (2015) have studied testing the effectiveness of conscious sedation for children with attention deficit hyperactivity disorder (ADHD) and learning disabilities.

Some guidelines and policies can be found online, created by the Dental Faculties of the Royal Colleges of Surgeons and the Royal College of Anaesthetists (2015). Please refer to NICE guidance when supporting people with autistic spectrum conditions regarding anxiety and prescribing medication.

Cognitive behaviour therapy (CBT)

CBT is based on the concept that your thoughts, feelings, physical sensations and actions are interconnected, and that negative thoughts and feelings can trap you in a vicious cycle. (Read here for more information: <http://www.nhs.uk/Conditions/Cognitive-behavioural-therapy/Pages/Introduction.aspx>.)

CBT works by breaking down the current problems into smaller parts and shows how to change the negative parts to improve how a person feels. CBT is used to treat anxiety and phobias through a course of therapy treatment that lasts between 30 minutes to 1 hour, over 5 to 20 weeks. This treatment may not be suitable for some people with complex mental health needs or learning disabilities as it requires structured sessions.

However Nadeau *et al* (2011) have identified that if adapted to the unique characteristics of youths with autism spectrum conditions and comorbid anxiety, cognitive behavioural therapy shows excellent promise. They identified further research is required.

There are two helpful documents in the Resources section: 'Progressive muscle relaxation (PMR)' and 'How to relax when you are out and feeling anxious or tense'.

Handout 1.3: Treatments and helpful strategies to reduce anxiety and phobias contd.

Useful resources

Centre for Clinical Interventions (2016a) *Progressive Muscle Relaxation* [online]. Available at: <http://www.cci.health.wa.gov.au/docs/ACF3C5B.pdf> (accessed April 2017).

Centre for Clinical Interventions (2016b) *What is Mindfulness?* [online]. Available at: <http://www.cci.health.wa.gov.au/docs/ACF3958.pdf> (accessed April 2017).

Cooke D & Wilcox M (2012) *How to Relax* [online]. Aneurin Bevan Health Board Learning Disability Psychology Service. Available at: https://www.easyreadhealthwales.org.uk/media/281218/how_to_relax_-_aneurin_bevan.pdf (accessed April 2017).

Easy Health (2010) *Anxiety* [online]. Available at: <http://www.easyhealth.org.uk/sites/default/files/null/Anxiety%20booklet.pdf> (accessed April 2017).

Mencap (2017) *Don't Miss Out* [online]. Available at: www.mencap.org.uk/dontmissout (accessed April 2017).

Stress Relief Exercises (2011) *Progressive Muscle Relaxation* [online]. Available at: http://www.stress-relief-exercises.com/progressive_muscle_relaxation.html (accessed April 2017).

Vivyan C (2010) *Using Music Therapeutically*. Available at: <https://www.getselfhelp.co.uk/docs/Music.pdf> (accessed April 2017).

Handout 1.4: What is desensitisation?

Definitions of desensitisation

Desensitisation is when anxiety is reduced by gradually getting used to the object or situation which causes fear (McLeod, 2015).

There are two behaviourist therapies used to treat phobias – systematic desensitisation and flooding. Both therapies use the principles of classical conditioning to replace a person's phobia with a new response – relaxation.

Systematic desensitisation, also known as graduated exposure therapy, is a type of behaviour therapy used in the field of psychology to help effectively overcome phobias and other anxiety disorders.

It is a form of counter conditioning, a type of Pavlovian therapy developed by South African psychiatrist Joseph Wolpe.

An individual is exposed to objects or situations which resemble the feared objects or situations. In a series of steps the individual is then guided towards the feared situation or object.

This gradual approximation works really well for lots of people and is a process often related to people who have specific phobias, such as spiders or dogs.

History of desensitisation

In the early 1900s Russian physiologist Ivan Pavlov used dogs to study the concept of classical conditioning. Pavlov knew that a dog salivates when eating. In his experimentation, Pavlov began to present a neutral stimulus, such as signal light or bell, before feeding the dogs. Obviously, the signal had no noticeable effect on the dogs' salivation. But Pavlov kept the signal on when the dogs were being fed (and actively salivating), and, over the course of time, Pavlov found that the signal alone, even without his offering food, gradually caused the dogs to salivate (Pavlov, 1897).

The reverse side to classical conditioning is called counter conditioning. This amounts to reducing the intensity of a conditioned response (anxiety, for example) by establishing an incompatible response (relaxation) to the conditioned stimulus.

In the late 1950s Joseph Wolpe developed a treatment program for anxiety that was based on the principles of counterconditioning. Wolpe found that anxiety symptoms could be reduced (or inhibited) when the stimuli to the anxiety were presented in a graded order and systematically paired with a relaxation response.

This process of reciprocal inhibition came to be called systematic desensitisation. Wolpe's systematic desensitisation program, as a practical application of his theories, proved to be highly successful in the treatment of 'neurotic anxiety'.

Many researchers have since concluded that exposure to the feared object or situation is the critical factor in treatment.

Handout 1.4: What is desensitisation? contd.

Research has shown that systematic desensitisation can be effective in treating fears, phobias, other anxiety disorders, and a wide variety of other mental health and behaviour problems.

The tools in this pack enable the desensitisation process to be achievable and practical for people with learning disabilities. Some individuals may experience mild anxiety because the screening equipment or the environment is new to them. Spending time with them so they become familiar with the equipment or new environment may be enough. Individuals who have very high anxiety around screening may need more intensive desensitisation work.