



Public Health
England

Protecting and improving the nation's health

Blood tests for people with learning disabilities: making reasonable adjustments

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

About the Public Health England Learning Disabilities Observatory

The Public Health England Learning Disabilities Observatory (PHELDO) was set up in April 2010 to provide high quality data and information about the health and healthcare of people with learning disabilities. We are also known as Improving Health and Lives (IHaL). This name was suggested for the Observatory at a consultation with self-advocates organised for the Department of Health by Mencap. The information helps commissioners and providers of health and social care to understand the needs of people with learning disabilities, their families and carers, and, ultimately, to deliver better healthcare. PHELDO is a collaboration between PHE, the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. Since April 2013, the Observatory has been operated by PHE.

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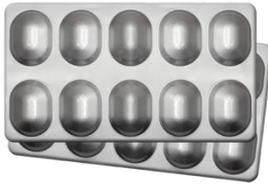
Easy-read summary



There are lots of reasons why someone might need to have a blood test.



Blood tests can show if people have some sorts of illness.



Blood tests can be used to check if treatment is working.



Some people with learning disabilities are scared of needles. This might mean they don't want to have a blood test.



The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities use services.

This means they need to change their services so they are easier to use.



This report has examples of easy-read information and films. These can be used to help people with learning disabilities who need a blood test.



This report has examples of how local services have put reasonable adjustments in place. These can help people with learning disabilities cope with having a blood test.

The pictures in this report are from NHS Photo Library and Photosymbols (www.photosymbols.co.uk)

Introduction

This guidance is to help health professionals who need to take blood from someone with learning disabilities. It may also be of use to paid social care or health staff and family members when they are supporting someone to have a blood test.

Under the Equalities Act 2010,¹ public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. This report is the 14th in a series of reports looking at reasonable adjustments in a specific service area (see Appendix A). The aim of these reports is to share information, ideas and good practice in relation to the provision of reasonable adjustments.

We searched for policy and guidelines that relate to people with learning disabilities needing blood tests. A summary of this information is below. We looked at websites to find resources that might be of use for people with learning disabilities who need a blood test but are very anxious about this.

We put a request out through the UK Health and Learning Disability Network, a major email network for people interested in services and care for people with learning disabilities. We asked people to send us information about what they have done to support people with learning disabilities to have blood tests that they need.

This report sets out what we found. Despite there being good reasons for many people with learning disabilities to be afraid of needles, such as past experiences of forcible administration of sedatives, there is little relevant research or policy. The report describes the online resources we found and where you can access them. This is followed by a selection of case studies and examples of reasonable adjustments made to support people with learning disabilities in tolerating blood tests. We had a very good response to our information request and as a result we have not been able to include all the examples of good practice that we were sent.

Blood tests for people with learning disabilities

Why is this an important issue?

There are a number of findings from the Confidential Inquiry into the Deaths of People with Learning Disability² (CIPOLD) that highlight the importance of timely blood tests for people with learning disabilities:

- problems with diagnosis and treatment were the most common reasons for premature deaths – blood tests are often a vital part of diagnostic investigations and can support a treatment pathway
- blood tests are important for monitoring the efficacy and side-effects of some medication – this includes anti-epileptic drugs, which are more likely to be prescribed to people with learning disabilities

Evidence and research

A literature search identified minimal relevant research. There is evidence that blood tests are one aspect of the annual health check that can cause anxiety for people with learning disabilities.³ A small study which involved talking to people following a health check found that most of them (81%) liked seeing their doctor but 34% indicated a dislike of needles or refused a blood test or vaccination.⁴ CIPOLD² found that almost a sixth (16%) of people with learning disabilities were described as having a significant fear of contact with medical professionals such that it might affect healthcare interventions. This included a fear of needles and it was recommended that such anxiety should be addressed by desensitisation work.

Since the introduction of the incentivised annual health check scheme for people with learning disabilities there has been an increase in the number of blood tests requested. A large study of data on over 8000 patients with learning disabilities showed that more blood tests were done by GP surgeries that were providing annual health checks.⁵

Research has identified concerns around informed consent in relation to blood tests for people with learning disabilities.⁶ This study found that consent procedures were often inadequate. An understanding of information about the procedure is an essential requirement for informed consent and in most cases this was not checked by the health professional. Participants reported needing clear, accessible information and simple verbal explanations without jargon being used. The authors highlighted the need for

healthcare professionals to have a good understanding of the consent process and the mental capacity act.

The literature search identified two published case studies. Obviously case studies only provide anecdotal evidence but they can be useful in illustrating the scale of the challenge in some instances and the diversity of solutions. The first described how a young woman with moderate learning disabilities and severe autism was supported to have a number of blood tests despite her phobia of needles.⁷ A desensitisation programme was developed, which necessitated a lot of input from the community learning disability nurse and involvement from Sara's family, her supporters, a speech and language therapist and a phlebotomist. The process is reported in detail in Edwards and Northway (2011).⁷ Although there were considerable time demands required, Sara was able to have multiple blood tests in different settings so her learning was maintained and transferred. This enabled a health problem to be diagnosed and hopefully will help Sara's access to healthcare in the long-term. Collaborative working between primary care and learning disability services was crucial to the success of this intervention.

The second described the input needed in order to get a blood test done for a 9-year old boy with severe learning disabilities and autism.⁸ It took 15 weeks and 7 appointments to get the blood sample and it was only successful with the input of an anaesthetist. The authors concluded that with better communication and planning the family could have had an easier experience. They recommended that professionals need to adapt existing systems to meet the specific needs of individuals and that this requires careful planning. We hope that the good practice case studies in this report will help provide some guidance on how this can be done successfully.

Policy and guidance

Clinical holding

We have not been able to identify any policy or guidance specifically addressing blood tests for people with learning disabilities. There is some guidance around clinical/therapeutic holding which may be useful to consider. The Royal College of Nursing has issued guidance for nursing staff on *Restrictive physical intervention and therapeutic holding for children and young people*.¹⁰ The Faculty of Dental Surgery has published *Clinical Guidelines and Integrated Care Pathways for the Oral Health Care of People with Learning Disabilities*.¹¹ Both documents are clear that clinical holding should be used as infrequently as possible and only when all other approaches have been tried or considered.

Some of the relevant principles from these documents are:

- clinical holding must be underpinned by an ethos of caring and respect for the individual's rights
- there should be a risk/benefit assessment prior to the intervention – this should include careful consideration of whether the procedure is necessary and if there are any alternatives to clinical holding
- there must be a sufficient number of staff who are appropriately trained and confident in the process
- accurate record keeping is essential – this should include why the intervention was necessary and details of what it involved

The dental guidance states that clinical holding is preferable to the use of a general anaesthetic. This should be considered as the ultimate in physical intervention as an unconscious person is unable to withdraw consent.

Consent

As with any medical intervention there are issues of capacity and consent to consider. In order for a person to have the best chance to make an informed decision about having an injection or blood test they need to be able to understand what the process involves and the implications of refusing it. Table 2 lists easy-read resources and films that can be used to support someone to understand the decision they are taking. If the person is assessed as not having capacity to take the decision then a best interests decision should be made in line with the Mental Capacity Act.

Reasonable adjustments

Avoidance

When someone with learning disabilities who is anxious about needles requires a blood test or an injection there should always be consideration of less invasive alternatives. This would include the use of the nasal spray flu vaccine. It should also include the possibility of a finger prick blood test as opposed to venepuncture. Finger prick blood tests can be adequate for haemoglobin tests, diagnosing and monitoring Type 2 diabetes and for limited thyroid testing.

People being prescribed antiepileptic drugs or lithium need therapeutic drug monitoring which is traditionally done via regular blood tests. It is possible for this to be done by checking saliva levels rather than blood levels and this could be a reasonable adjustment for someone with learning disabilities who is anxious about needles.

Preparation

For people who have needle phobia and are in need of an injection or blood test the first approach is generally desensitisation work. This is usually a systematic programme supporting the individual to relax and gradually introducing them to the feared stimulus. It is about building up the individual's confidence at each stage, until they are ready to have the blood test. It might start with someone getting used to the environment and then over time being exposed to the equipment and then the different steps of the process. With sufficient repetition through practice, the anxiety around the injection or blood test can be reduced.

Amelioration

Other reasonable adjustments may include the use of topical applications to numb the skin prior to needle insertion. These include:

- Lidocaine and prilocaine cream – needs to be applied at least an hour before needle insertion and must be covered with a plastic wrap
- Tetracaine gel – needs to be applied 30-45 minutes beforehand and should not be left on for longer
- Ethyl chloride – this provides local pain relief when sprayed topically onto the skin. It has no anaesthetic properties but rather works as a vapo-coolant. It is applied immediately before needle insertion. It can be very useful for those who are allergic to topical anaesthetics, or for those who get very upset when the cream is applied before tests

The Step-by-step guide to Health Checks for people with a learning disability^a from the Royal College of GPs provides further information on the use of topical applications.

We have been sent many good practice examples where alternatives to needles have been considered or where people have been supported to tolerate them. A selection of these is presented later in this guidance.

^a <http://www.rcgp.org.uk/clinical-and-research/toolkits/health-check-toolkit.aspx>

Resources

The three tables that follow list all the information and resources we have found in relation to supporting people with learning disabilities to have blood tests.

- Table 1 lists websites and resources that may be of use to professionals/family members and carers who want more information and resources
- Table 2 lists the easy-read resources and films we have found. This is where you can find information to use with people with learning disabilities
- Table 3 lists the relevant free apps we have found about having blood tests or injections

Some resources may be available from more than one site, but we have only given one link. We have only included resources that are free to download, although some of the websites may also include resources you can buy.

Table 1: Resources about blood tests for professionals/family members and carers

Theme	Description	Provider	Link
Health Facilitation Service: Supporting people who have a learning disability to give a blood sample	An example of a leaflet advertising the health facilitation service and how they can support people with learning disabilities to give a blood sample	East London NHS Foundation Trust	https://www.ndti.org.uk/uploads/files/Health_Facilitation_Service__Supporting_people_who_have_a_learning_disability_to_give_a_blood_sample.pdf
For Families and Carers : Giving Blood Samples	Webpage with some tips that may help children and adults have a better experience of giving blood samples	Down's Syndrome Association	www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/giving-blood-samples/

Table 2: Easy-read and accessible resources about blood tests/injections

Theme	Description	Provider	Link
Blood test card	An 8 page easy-read leaflet showing the stages involved in a blood test. It has large	Hull and East Yorkshire Hospitals NHS Trust	http://easyhealth.org.uk/sites/default/files/blood%20test%20card_0.pdf

Theme	Description	Provider	Link
	font and clear photos		
Blood test	An easy-read leaflet with pictures about having a blood test	Chardie EasyRead	http://easyhealth.org.uk/sites/default/files/null/Bloodtest.pdf
Fasting blood test	A one page sheet about what to do before a fasting blood test	Unknown	http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/acute-hospitals/treatments-procedures/Fasting_Blood_Test.pdf
Having a blood test	An easy-read leaflet with photos about having a blood test	Gloucestershire Hospitals NHS Foundation Trust	http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/primary-care/treatments-procedures/Having_a_blood_test_GHPI1150-04-12.pdf
Having a blood test	An easy-read leaflet with photos and symbols about having a blood test	Devon Health Awareness Group	http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/primary-care/treatments-procedures/Having-a-blood-test1.doc
Having a blood test	A photo-story about having a blood test	Royal Cornwall Hospital Trust	http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/acute-hospitals/treatments-procedures/Having_A_Blood_Test.pdf
Going for a blood test	Booklet giving information and photographs of the process of going for a blood test.	Hampshire Partnership NHS Trust	http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=108
You are having a blood test	An easy-read leaflet with photos that gives information for patients about having a blood test	Mid Yorkshire Hospitals NHS Trust in partnership with Wakefield Learning Disability Partnership Board	http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=162
Easy Read Patient Information - Having a Blood Test	A 7-page easy-read leaflet with photos about having a blood test	Chesterfield Royal Hospital NHS Foundation Trust	www.chesterfieldroyal.nhs.uk/dl/10264_4180732163.pdf/as/Having%20a%20Blood%20Test%20-%20Easy%20Read%20Patient%20Information.pdf?_ts=1464&_ts=1464
Having a Blood	An easy-read leaflet by	Dorset Healthcare	https://www.ndti.org.uk/upload

Theme	Description	Provider	Link
Test	the Intensive Support Team about having a blood test	University NHS Foundation Trust	s/files/Having_a_blood_test.pdf
Getting a blood test - social story	This is an American resource aimed at children with learning disabilities. It is a social story about having a blood test	One Place for Special Needs	http://www.oneplaceforspecialneeds.com/main/library_blood_test.html
Having a blood test	A 3-minute information video for people with learning disabilities that require a blood test	Derby Teaching Hospitals NHS Foundation Trust	https://www.youtube.com/watch?v=0AVkU9Hs7VM
Blood test	A short film about having a blood test	My HealthVision	https://www.youtube.com/watch?v=5NEpFtEpkQg
Having a blood test at Bedford Hospital	A six-minute film about having a blood test at Bedford Hospital	Bedford Hospital	https://www.youtube.com/watch?v=91ejfkeE08E
What happens when you have a blood test?	A 3-minute film about having a blood test at a GP surgery	Swansea People First	https://www.youtube.com/watch?v=olQf2aVG-kQ

Table 3: Apps related to blood tests

Theme	Description	Provider	Link
Blood Test	This app is designed for people with learning disabilities who are due to have a blood test. It is in an easy-read format with colourful clear graphics, large text and supporting narrative audio	Christopher Hardy	https://itunes.apple.com/gb/app/blood-test/id960832103?mt=8
Pablo the Pufferfish app	This app is designed to help children overcome their fear of needles by distracting them with something fun. It is an interactive storybook which follows Pablo the Pufferfish as he learns to overcome his fear of needles. It includes puzzles and games	Healthline	http://www.healthline.com/health/big-shots-get-shots-iphone-application#.WCRLXS2LTcs https://itunes.apple.com/us/app/overcome-fear-needles-pablo/id588549144?ls=1&mt=8

Examples of reasonable adjustments and case studies

We had a lot of responses to our information request for examples of good practice in relation to blood tests and injections for people with learning disabilities. The majority of these were stories which described desensitisation work as well as reasonable adjustments that were put in place for the individual. Below are some of the examples we were sent.

Desensitisation work

One example of desensitisation was sent to us by an Occupational Therapist who worked jointly with a nursing colleague:

Central and North West London NHS Foundation Trust

“We visited the community client twice a week for 4 weeks prior to the blood test and gave a massage to the arm (this increased the blood flow to the arm). By offering massage you can build a rapport and trust. We played her favourite music and she got used to the person giving the massage. After the first two visits, we introduced the elastic band and placed this on the arm (without tightening it) and continued with the massage. The 3rd week we started to tighten the band very slightly and gave the massage.

We then supported her when she went for a blood test and gave the massage before the blood was taken. She had her favourite music whilst this was happening.”

For further information please contact Hayley Goodwin, hayleygoodwin@nhs.net

Whilst most of the examples we were sent about desensitisation describe work done with individuals we have also been told about a large-scale desensitisation programme:

Care Trust’s work in schools in Bradford, West Yorkshire

Tina Wildy is a nurse specialist at Bradford District Care NHS Foundation Trust, and supports children with learning disabilities and autism in schools. She has designed and delivered sessions on immunisation preparation, to better support children with learning disabilities in Bradford.

At one school for children with profound autism she designed a large-scale desensitisation programme, delivered on a weekly basis. This work has only been possible because the school have been very supportive of the Care Trust’s input. They

start this work with children as soon as they begin in reception year and they use a 'four-stage mantra' to support the children's learning:

- sleeve up
- sit still
- no looking
- injection

This is supported with visual images, using Boardmaker software, and is repeated verbally to the children at each step. A very small number of children cannot tolerate the verbal approach, so are simply shown the images.

With very young children, the specialist nurses use the nurse rhyme 'round and round the garden' as an approach to support immunisation. They start doing this whilst just holding a syringe in their hand and using their fingers, then progress to using the syringe to touch the back of the child's hand. When they take the 'one step', they touch the child inside the elbow to help prepare them for accepting blood tests. To end the rhyme, instead of saying 'tickle you under there' they say 'injection over there' and touch the child's arm at the injection site. They found that 5ml syringes were the best to use - small enough not to intimidate and strong enough to endure mouthing, if a child inadvertently holds one.

Initially, working with every child in the school was time-consuming but the Care Trust now has an established routine, so they only need a brief amount of time with most children. One nurse is able to see 80-100 children in around two and a half hours.

When introducing older children to this programme, they use syringes to dribble water on the back of their hands and work on desensitising them in this way. The nurses still use a story approach and visual images which act as a reminder of each of the four stages. The four-stage mantra helps the children get used to the process and repetition is fundamental to the success of this work.

In the more 'generic' special schools, sessions are tailored to different levels of understanding. All members of the Care Trust's school nursing team now deliver these sessions. In these schools, it is usually enough to deliver structured group work annually, prior to the flu vaccinations. All classes in a school can usually be seen in a single day, however some children will still require more intensive desensitisation work and so one-to-one input is offered where needed. This usually involves home visits and working with the child's parents, so that they can undertake the desensitisation work themselves. With children who are very fearful, it is essential that the child feels in control and this may mean taking the process very slowly.

The nurses' approach centres on helping the children to:

- understand why they are having an injection

- know what is happening
- feel in control in order to reduce their fear

They have found that working with everyone in the school is very effective and that peer support is an important element of this. The nurses give lots of praise to the children and it is evident that many of the children are very proud when they are able to have an injection.

In order for the children to understand what the process involves they use stories, puppets and video clips that are all available on the internet. A crucial aspect of their work is empowering the children and reinforcing a general safeguarding message that it is always ok to say 'no' when someone is asking to touch you. In that situation, the nurse would say: "Ok, not today, let's try next time". Although the school nursing team wants children to become unafraid of injections, they also give a clear safety message of the importance of never touching syringes. In the sessions they emphasise never to pick one up and to tell a grown-up if they find one.

During administration of actual injections, the nurses try to be very quick to minimise anxiety. Along with the 'mantra' and symbols, they also use distraction and the puppets that are used in the group sessions in the 'generic' special schools to help the children become familiar with the process. Overall, the Care Trust's specialist nursing team has found that working with children from an early age can help them to cope with future injections and blood tests.

For further information please contact Tina Wildy, nurse specialist at Bradford District Care NHS Foundation Trust, tina.wildy@bdct.nhs.uk

Below is a case study about how a working group was set up to develop a pathway for blood desensitisation work and resources to support this.

Multidisciplinary blood desensitisation group, North Wales

In North Wales practice nurses had been requesting guidance from the Community Learning Disability team (CLDT) around capacity and consent when taking blood from people with learning disabilities. It was evident that community learning disability nurses were all working individually, often with different approaches. Consequently, a health liaison nurse set up a multidisciplinary working group to develop a blood desensitisation pack and pathway.

The group membership included representatives from the following teams:

- Health Liaison Team – they led the meetings and owned the project
- CLDT
- Complex Needs Service

- Health care support workers
- District nursing
- Enhanced community residential services
- Phlebotomy
- Psychiatry

The group met 6 times over 18 months to develop the pathway and the flow chart and discuss issues around capacity and consent. The pathway addresses best interest discussions, sedation, restraint, risk assessment and advocacy. It was agreed that if restraint was needed, the complex needs service would offer support and consultation around the necessary training for this. The complex needs service also assisted with the documentation of a short-term restraint protocol.

The blood desensitisation pack contains:

- flash cards
- goal chart
- stop cards – to allow the person to communicate if they want the session stopped
- emotion cards
- blood taking support plan
- desensitisation pathway and guidelines
- top 10 tips for alleviating pain/anxiety
- lidocaine and prilocaine cream instructions

Further details about the development of the pack including a case study example can be found at <http://www.independentnurse.co.uk/professional-article/blood-desensitisation-pack/63680/>

The team have found that the desensitisation pack is a useful tool for supporting people with learning disabilities when they are anxious about blood tests. They are currently auditing the use of the pack.

For further information please contact Kim Scandariato,
Kim.Scandariato@wrexham.gov.uk

Personalised reasonable adjustments

One basic reasonable adjustment that can be made is a home visit. A home visit takes more time for the professional but in the long run it can be quicker and more effective than multiple unsuccessful attempts at the GP surgery. Below is a case study describing an effective home visit.

Berkshire Healthcare Foundation Trust

Following an annual health check it was identified that a young man with learning disabilities and severe autism, high anxiety, increased sensitivity to sounds and sensory integration difficulties required a blood test due to various health needs.

The learning disability nurse discussed with his family how this could happen and suggested they begin to prepare him for the blood test. The nurse created a personalised social story with photos which showed all the steps of the process. The nurse also suggested the family could use clips from YouTube to show what was going to happen. The family decided it would be useful for them to role play what would happen to help him stay still and keep his arm out straight.

The GP practice was unable to do a home visit to take the blood. The learning disability liaison nurse from the local hospital said they could support him to go to the hospital for the blood test. However his anxiety and problems with noise meant that leaving the house was extremely difficult. Therefore the learning disability nurse spoke to the community children's nurse (CCN) team who said they were able to help with doing the blood test at home. They liaised with the specialist tuberculosis nurses so they could do this blood test at the same time without another nurse needing to come along.

On the day of the blood test, the learning disability nurse met the CCN at the family home. The young person was in his bedroom where he felt comfortable. The nurse went upstairs to show him the equipment. His mother and sister had been going through the story with him and had pre applied the lidocaine and prilocaine cream.

When all were ready, his mother laid behind him to help hold his arm out if needed and reassure him. The nurse was able to take the blood test while talking to him and the learning disability nurse role modelled to him about keeping his arms out straight during the test. The nurse was able to get all the tests needed with no problems. He coped extremely well and showed no difficulty or stress from having the test. He got some of his favourite sweets afterwards and everyone said how well he did. His mother was thrilled with how well the procedure went.

For further information please contact Katherine Burns,
Katherine.Burns@berkshire.nhs.uk

Hertfordshire

We have been sent several examples of good practice from Hertfordshire. The reasonable adjustments that they have used successfully include:

- thyroid testing using a finger prick sample - the GP link nurses are now actively promoting this with other GP surgeries

- working with the health liaison team to arrange to have the blood test done at the children's ward rather than in the phlebotomy department – this is a nicer setting with lots of distractions
- doing blood tests at home for people who do not like hospital/surgery settings
- several meetings with a learning disability nurse to build up a rapport and to discuss the need for the blood test using easy-read information
- a request for a female phlebotomist and a visit to meet her prior to the procedure
- the use of lidocaine and prilocaine cream to numb the arm
- the use of an iPad to watch videos of blood tests
- double appointments at the GP surgery to ensure it was not rushed
- two appointments booked in the same week in case the first appointment was not successful
- appointments booked for the quietest time at the GP surgery so the person did not have too long to wait and did not have time to become anxious
- a screen used in the nurse's room to ensure the person would not see the needle

Further details about one of these case studies can be found at

<http://m.hertfordshire.gov.uk/docs/pdf/p/purpnewsaut.pdf>

Another reasonable adjustment that we were sent multiple examples of was the use of ultrasound:

“Our daughter has very small veins and it has proven extremely difficult to take bloods. After spending days travelling between GPs, district nurses and a chemotherapy ward it became ridiculous and very frustrating. I approached our learning disability nurse who made enquiries. Since then whenever our daughter needs blood tests we arrange it with the IV team at our local hospital who use ultrasound to locate the veins. This has proved to be a much needed reasonable adjustment which has been extended to others with similar issues.”

Below is a case study which illustrates how a combination of desensitisation work and reasonable adjustments can be used to support someone to cope with a blood test:

Tower Hamlets Learning Disability Team

The community learning disability nurse (CLDN) met with Peter, his father and his supporter and talked about things that Peter likes to do. He always carries a package with him as he likes to think of opening and closing the package. This was very important to acknowledge as it would be the resource that would be used leading into the blood test day. The CLDN planned to meet weekly with his regular supporter for 6 weeks. It was agreed with Peter's GP that all possible blood tests would be carried out and the blood form was completed appropriately and passed on to the phlebotomy team.

The CLDN communicated with Peter using pictures and Makaton signing. The nurse used the United Lincolnshire Hospitals NHS trust 'Having a blood test' easy-read booklet. The front page was not shown at any stage of the process to Peter as it was too explicit with the picture of the needle going into the arm. The CLDN met Peter every week in her office at the hospital and walked over to the phlebotomist at an arranged quiet time. Peter loved picking a ticket at the outpatients as it was in the sequence of pictures in the easy-read booklet, that he was able to follow.

One week he was encouraged to sit in the chair in preparation for the blood test and the next he managed to sit in the chair and remove his coat. It progressed week by week until the tourniquet was placed on his arm. It was arranged that the CLDN would stand in a particular position to block Peter's vision of his brachial veins. It was assessed during this time which arm had the best veins. This was very important as the lidocaine and prilocaine cream needed to cover the chosen arm and area for the day of the blood test. At the end of each session they always went to the local café in the hospital to ensure that each visit was a pleasant experience.

The staff at his home were also carrying out arm massage daily on the identified arm and applying Vaseline (in preparation for the lidocaine and prilocaine cream) to his arm with a plaster but he refused to wear the plaster.

On the morning of the blood test lidocaine and prilocaine cream was applied on his specific arm and a long sleeved shirt covered the arm so that he could not touch the area as he would not tolerate a plaster. His father came for support. Peter went through the full ritual as practiced weekly and when it came to the actual needle going in, the CLDN was able to block the area from view and gentle holding was applied by his father. The blood test was successful and they all had a celebration in the café in the hospital as normal.

The success of this was dependent upon the staff, family and phlebotomist all agreeing to the weekly commitment. It was very important that the weekly timing of the meeting allowed Peter to take control and build up trust in all the people who helped facilitate this process.

For further information please contact Marie Houston,
Marie.Houston@bartshealth.nhs.uk

Less invasive options

If having venepuncture is very difficult for an individual then consideration should be given to less invasive options. We have been sent many examples of where a finger prick blood test has been used successfully:

Lab in a box

Healthcare Scientists in the north west are looking at ways to take their diagnostic services out of secondary care and make diagnostics more accessible to patients with learning disabilities in order to improve their physical health. They were involved in an 'Our Health Day' at Chorley hospital which was attended by about 100 people with learning disabilities.

Dr Martin Myers and his pathology team took along their 'lab in a box' to the event and screened people with learning disabilities for common, and treatable, conditions such as diabetes and high cholesterol. This is the latest technology in diagnostics and is an example of point of care testing (POCT). This is defined as any form of diagnostic testing undertaken outside a laboratory environment. It is about bringing the laboratory technology into an environment that meets the needs of the patient. This technology uses a small amount of blood from a finger prick, so it is not as intrusive and painful as venepuncture. This can reduce the stress and anxiety that is often associated with having a blood test, but still provide accurate results.

At the health day in Chorley hospital the team tested 37 people with learning disabilities and this picked up a number of people who needed to go and see their GP. The 'lab in a box' can be a successful way to undertake simple diagnostic testing for diseases that can be easy to treat, but can be fatal if they are not diagnosed and treated. The Chorley learning disability health day will be repeated in 2017, during learning disability week, and it is hoped that the 'lab in a box' model will be used in different parts of the country as well.

You can watch a short film about the health day at

<https://www.youtube.com/watch?v=4nIBIglW5w4> or <https://vimeo.com/173881352>

For further information please contact Martin Myers, martin.myers@lthtr.nhs.uk

Nottinghamshire Health Care NHS Foundation Trust: Primary Care Liaison Nurse Team

In Nottinghamshire the Primary Care Liaison Nurses (PCLNs) noticed a sharp increase in the number of referrals from GP practices, signed up to the enhanced scheme for annual health checks, to support people with learning disabilities access venepuncture services.

For some people referred to the team the only extra support they needed might be as simple as providing information in a format the individual understands to make an informed decision about having a blood test.

For many other people the team can support them to get to the point of having a blood test via venepuncture by a programme of systematic desensitization. They help the individual to relax and gradually introduce the person to the equipment used in

venepuncture, building up the individual's confidence at each stage, until they are ready to have the blood test.

For those people for whom this is not sufficient they have used other supporting strategies such as the use of topical anaesthesia to reduce the sensation of needle penetration and/or medication to reduce an individual's anxiety prior to being bled via venepuncture. They have also had much success with a palm sized device that combines both cold and/or vibration to significantly reduce the pain and fear often associated with venepuncture. This 'buzzy bee' device was developed by a paediatrician to support children who had a fear of needles. Further information about this device can be found at www.buzzy4shots.co.uk/

Despite their success in supporting the majority of people referred for support in relation to having a blood test, there remains a number of individuals for whom being bled via venepuncture causes such distress, risk or anxiety that having a blood tests just did not happen. In such cases they have found that dried blood spot testing or point care testing could often be a solution. This method of testing offers the least invasive method of supporting having a blood test and it can be performed where the patient feels most at ease and by someone who knows the person well. They found point of care testing was useful for checking haemoglobin levels, glucose levels and thyroid stimulating hormone levels.

For further information please contact Maureen Major, maureen.major@nottshc.nhs.uk

Adult Learning Disability Service, Bridgewater Community Healthcare NHS Foundation Trust

Capillary Blood collection project – Wigan Locality area

This project was set up to increase the completion of blood tests for people with learning disabilities, who had previously been unable to tolerate blood collection in the conventional way – via venous collection (a needle in the arm). Some of these people had required sedation due to their anxieties or challenging behaviours. An Assistant Practitioner from the Adult Learning Disability Service worked collaboratively with a Senior Phlebotomist in an Acute Trust at Wrightington, Wigan and Leigh NHS Foundation Trust to develop clinics for the completion of blood tests via the capillary blood collection route. This involves using a lancet device to make a small incision to the side of the finger and then squeezing the finger to obtain small samples of blood via micro tubes and lancets—only small blood samples are required. This procedure is ideal for a lot of people with learning disabilities as it a relatively minor invasive procedure with low risk of any injury.

Prior to the procedure the person would usually require a programme of desensitisation sessions. These include a number of different strategies and sessions at home, day services or in a clinical environment. Different strategies are used dependant on the person's fears or the barriers identified. Accessible visual information is sometimes used to go through the procedure, picture exchange, social stories, hand massage and

using props – such as tourniquets and lancets and clinic visits. The aim is to increase the level of graded exposure until the patient is ready to attempt the blood collection in the appropriate environment. This usually takes around 4-8 weeks.

Consent is either implied or verbal from the person and in some circumstances they complete a best interests decision making form, signed by the clinician, family and named nurse or health professional (in the case of this project the nurse practitioner or consultant psychiatrist).

A case study in the early stages of the project involved a young man with autistic spectrum disorder and cerebral palsy who had negative experiences of blood tests. This involved a period of desensitisation and gradual exposure. After this period of exposure they were able to introduce him to the phlebotomist in clinic. Support around completing his blood tests included the following:

- demonstration of the capillary bloods procedure – for supporters
- getting family/supporters on board in terms of trust due to negative experiences
- liaison with GP practice and phlebotomy to coordinate sessions
- verbal and implied consent was gained from the person who cooperated with the desensitisation and the procedure
- giving him a clinic tour
- providing a fact sheet for him and his supporters which was about the preparation for the procedure
- completing a number of desensitisation sessions at home using visual information, props and graded exposure using tourniquet, lancets and anaesthetic cream
- using a social story to help talk him through the procedure in preparation for attending the clinic
- feedback to GP practice after blood tests were completed and guidance around future blood tests

In the initial pilot project the phlebotomist would complete the procedure while the assistant practitioner got all the equipment ready, reassured the person, kept their hands steady and checked on any potential behavioural problems. Sometimes carers or family were involved as well.

The assistant practitioner was subsequently trained to enable him to complete capillary procedures in a clinic setting or in the community. The adult learning disability service has continued to develop this project in a community setting and has increased the scope to reach more people. They are working collaboratively with GP practices to target people who may never have had blood tests completed. They work with the psychiatric outpatient clinic to identify people who will not attend a clinic setting due to behavioural problems.

They have had a good success rate in terms of obtaining bloods with the majority completed via the capillary route. When this has not been possible some people have been able to tolerate a traditional blood test in a clinic after desensitisation work. Most people will have anaesthetic cream prescribed and some may still require prescription of a sedative, authorised by a GP or consultant psychiatrist.

The assistant practitioner has developed a training package around capillary bloods competency and is cascading this to other colleagues in the adult learning disability service. The key aim of the project is for people with learning disabilities to have a more positive experience around blood tests and hopefully to make blood tests easier in the future.

There is further information about this clinical project at

<http://www.bridgewater.nhs.uk/wp-content/uploads/2012/11/Case-Study-Capillary-Blood-Test-Collection-Project.pdf>

For further information please contact Andy Hogg, Andrew.Hogg@bridgewater.nhs.uk

Safe-holding and sedation

As discussed earlier in the report there will be people who cannot tolerate a blood test even following desensitisation work and the implementation of reasonable adjustments. In such situations a more intensive approach may be needed. Below are two examples we have been sent which describe working with people who may need additional input such as safe-holding or sedation.

Dorset HealthCare Intensive Support Team

Mark is the learning disabilities nurse who works with the intensive support team in Dorset HealthCare University Foundation Trust. His speciality is supporting people with blood tests if there is a clinical reason for this level of input. This is evidenced by three previous failed attempts at taking blood. There is a clinical based pathway for these referrals (available at

https://www.ndti.org.uk/uploads/files/PATHWAY_FOR_BLOOD_TEST_VIA_THE_INTENSIVE_SUPPORT_TEAM_v2.pdf)

They have best interest paperwork to use in relation to following the Mental Capacity Act. This can be downloaded at

https://www.ndti.org.uk/uploads/files/MCA_Best_Interests_Decision_for_safe_holding_and_medical_treatment_v2.pdf.

The person's capacity to consent is assessed and if they are not able to give consent then a best interest process is started, which includes the GP, carers, family members, the person and all relevant professionals. Recent medical history and current medication are recorded on the best interest form. All these forms are completed prior to starting any desensitisation work.

The first step is a planned desensitisation programme which is individually designed to work with the individual with a planned date for completion. The only exception to this is if there is an urgent clinical need for the blood test.

There are three possible options when the GP has already had 3 failed attempts and subsequent desensitisation has been unsuccessful:

- safe-holding only
- sedation only – the GP will decide what medication to use but usually in consultation with the intensive support nurse and community nurse. This will be a small dose of a sedative such as lorazepam or diazepam
- safe-holding and sedation

They have had a lot of success with this approach. Mark has worked with a young woman who has severe autism who required regular blood tests due to her thyroid problem. Initially she required safe-holding and medication but after a year of regular blood tests in the same place, done by the same person she would roll up her sleeve when he walked in the room. She was subsequently discharged and district nurses took over but within 6 months she was referred back. After two attempts she was again co-operative with the blood tests.

There are a number of reasonable adjustments they make which help to ensure the success of their input. These include:

- home visits - people are likely to feel more relaxed in a familiar and safe environment
- giving people time to talk about the blood test and ask questions
- using social stories to help people understand what is going to happen
- an easy-read form for blood collection
- some people like to listen to music or watch cartoons during the process - Mark has even performed a dance to Disney's 'Frozen'
- providing a reward for person so that something positive happens following the blood test.

They are able to use needles which have a flash of blood that provides immediate confirmation that the needle has gone into the vein. Mark can also use a butterfly needle. This reduces the discomfort for the person as this is more accurate and effective, again reducing stress and anxieties for the person having the blood test. The team works alongside a dental surgery that does sedations for patients when necessary. They work collaboratively and take a proactive approach. Therefore if someone needs sedation for dental work they will look at doing a blood test at the same time. They have previously co-ordinated a hair-cut, a blood test and nails being cut when someone who was sedated for dental work.

The service has seen an increase in referrals from GPs and consultants when annual health checks have required a blood test and also they are often involved in supporting blood tests for people with Down's syndrome as part of dementia assessments.

For further information please contact Mark Fitch, mark.fitch@dhuft.nhs.uk

Bristol South Community Learning Disability Team

Steve is in his 20s and has severe learning disabilities and a history of unsettled, agitated and challenging behaviours, though he is rarely aggressive. He lives with his parents and is independently mobile. In recent years, Steve has become less co-operative with health related interventions and treatments such as blood tests, injections, dental, oral and personal care.

Steve was diagnosed with thyrotoxicosis which required regular follow-up blood tests. Recent blood tests over the last 2 years had required considerable restraint and struggling with him by his GP, parents, practice nurses and other health professionals. His GP felt that this was compromising her relationship with Steve as he found it very distressing and there was a risk of injury to him and others. A best interests meeting agreed that core staff members would be trained in clinical holding techniques and strategies.

There were significant delays while an organisational Reducing Restrictive Practice policy was drafted and agreed, and core staff were trained in CPI CH-3 Skills for Clinical Holding. The team identified to carry out the intervention were:

- Steve's community learning disability nurse (CLDN) – it was felt very important to have a health professional involved who knows Steve and his family
- an occupational therapist assistant and another CLDN - also Holding Skills trainers
- a learning disability healthcare assistant (HCA) trained in phlebotomy

The team met twice prior to the first visit to discuss the plan, practice possible holds and prepare for likely scenarios. As Steve's response was difficult to predict there was a need for flexibility and clarity in decision-making during the intervention.

The team undertook desensitisation work with Steve over 2 visits. They practiced low and medium level holds. He was able to wriggle out of initial restrictions which prompted them to focus more on the key principles of CH-3 Skills for Clinical Holding and consider their position, posture and proximity. This meant minimising any possible gaps and positioning themselves very tight on either side of Steve. Steve did not seem to mind this level of contact. The team spent significant time getting advice from Steve's parents about the best way to interact with him. For example they found he likes to hold hands/clap his hand against others and hug. They also used easy-read information to explain the plan to Steve. Part of the desensitisation work included the HCA showing Steve her blood-collection equipment (tourniquet, tray, bottles). They decided to approach the intervention openly with Steve so he would most likely have some awareness of what the team intended to do.

Detailed care plans and risk assessments were written up, agreed and signed by all clinicians and health professionals involved. They liaised with the GP, consultant

psychiatrist and dietitian about exactly what bloods were needed and as 3 blood bottles were to be used, the order of priority.

On the day of the planned intervention Steve had been given his usual breakfast and plenty to drink and had lidocaine and prilocaine local anaesthetic cream patches prior to the team's arrival. They had allowed plenty of time for Steve to greet them, get used to their presence, and settle down. Steve was reassured by his father who removed the lidocaine and prilocaine patches. The team chose the shortest sofa so there was a tight fit with one person either side using low then medium hold. The third person was able to stabilise his arm so the tourniquet could be applied and blood could be taken. Steve did not show any signs of distress or attempts to resist. He watched closely what was going on throughout and was not easily distracted. On the first attempt the vein collapsed but as Steve was calm they persevered and on the second attempt they managed to fill almost half the first bottle but then the blood stopped flowing. They agreed at this point to conclude intervention, as blood had been obtained and Steve had been held for approximately 2-3 minutes with the tourniquet. They felt this was long enough and also as he had been more co-operative than expected the team felt confident that repeating intervention at another time would have a good chance of success.

Steve did not appear distressed or in pain at any point or immediately after the procedure. He returned to walking around, interacting through touch and clapping and his parents were happy with the outcome, provided there was sufficient blood to test (it transpired there was). His CLDN rang Steve's mother later in day and she reported he had been his usual self the rest of the day and there was no sign the procedure had upset him.

Post intervention the team met to reflect on the experience and discuss any learning outcomes. The CLDN continued to liaise with Steve's GP about follow-up bloods.

For further information please contact Graham House, graham.house@nhs.net

Auditing blood test services

The final case study we have been sent describes how an audit was used to explore how the system for blood tests was working for people with learning disabilities. Following the audit the team was able to make suggestions about how to improve the way in which phlebotomy is requested for people with learning disabilities.

Nottinghamshire Healthcare NHS Foundation Trust

In Nottinghamshire they undertook a local audit to explore if there was any disparity in relation to blood tests for people with learning disabilities. They retrospectively looked at all outpatient letters for people seen in either the outpatient clinic or on community visits

over a 2 week period. If there was a request for phlebotomy they then searched electronic databases and contacted the phlebotomy laboratories for blood results. The accepted standard is that all requested blood tests should be completed within 2 months. They found that:

- 31% of blood tests requested were not attempted
- of the 69% of tests that were attempted there was incongruence between blood tests requested and the blood tests completed for a significant number of people

They subsequently recommended that when phlebotomy is requested by any clinician in an outpatient/community setting it should be communicated in two ways:

- the request should be conveyed in written form and recorded in the summary care plan - clinicians should be specific with regards to which tests they need completing, the rationale for the test request, and when it should be completed and reviewed by the GP
- a blood test request form should be fully completed with patient information and the blood tests requested for the patient/carer to take to their GP

They are planning to re-audit this in the future.

For further information please contact Asha Mashru, Asha.Mashru@nottshc.nhs.uk

Conclusion

Blood tests play an important part in assessing, monitoring and treating the health of people. Therefore it is important to find a way to make the procedure possible, even for people who are needle phobic. This guidance has signposted a lot of resources that can be used to support people and the range of case studies have illustrated approaches that can help. In summary there are a number of steps that should be taken when giving a blood test to someone with learning disabilities:

- Work in accordance with the Mental Capacity Act – start with a presumption of capacity, provide accessible information about the procedure to help someone take the decision and make a decision in their best interests if appropriate
- Remember that not everyone is worried about needles. The person should be asked neutrally if they are happy to have a blood test
- Always find ways to avoid needles if possible – use a finger-prick test rather than venepuncture if this will be sufficient
- Work with the person to desensitise them. It is likely that most people will face a situation where needles are required at some time. It can be easier to be proactive about this and prepare someone rather than address their needle phobia in an emergency situation
- Always use skin numbing creams
- Organise a local familiar place where people can go for blood tests when they need to. This should involve the most skilled practitioner for taking blood
- Prepare and reward if possible
- Sedation and restraint should only be considered when all other practical steps have been taken and are unsuccessful. A decision to proceed with this needs to be taken in the person's best interests and the reasons for this intervention must be clearly documented

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