

## Top Tips - guidance for GP practices supporting people with learning disabilities who have cancer

Below are some advice and tips for supporting people with learning disabilities through a cancer pathway. These suggestions are intended to complement formal training and professionally acquired experience of working with this cohort of patients. They are aimed at GP's, Practice Nurses, administrators and support workers involved in the cancer treatment pathway.

Stage in pathway	Helpful action	Not so helpful
<b>First GP Appointment</b>		
<b>Symptom discussion</b>	Consider diagnostic over-shadowing in a person with a learning disability. Changed behaviours/habits can suggest a person is in pain or having difficulties, which are known as 'soft signs' (going off food, sleeping a lot, being angry or distressed). People with learning disabilities often present differently. Pain may be difficult for the person to describe especially if they are non-verbal.	Don't disregard a carer or family member's perception that there is something wrong with the person. Family members and/or staff usually know the person very well and can tell when someone is not their usual self. Cancer studies show that people with learning disabilities are often diagnosed late due to communication difficulties
<b>Physical examination</b>	How much explanation is required will be different with every individual. Too much explanation can increase anxiety levels as can too little. Involve the carer in the explanation. Respect a person's wishes. If they do not want to be examined, make a referral to the Sirona Adult Learning Disability Health Service who may be able to offer support.	Don't do anything too quickly. Take your time with explanation and movements. People with learning disabilities can be extremely anxious about new situations/ circumstances or around health care professionals in general. Carers or staff present can usually calm the person or use distraction techniques
<b>Outcome discussion</b>	Look at the person and also involve their carer/staff. Explain as simply as you can what you think might be wrong and what will happen next	Don't use complex medical terms or complex language that the person might not understand.
<b>Referral to new service discussion</b>	Explain next steps clearly and emphasise key parts of the next stage. Make sure that the person and any carer feel able to ask questions. Consider a referral to the Sirona Adult Learning Disability Health Service - they may be able to help prepare the person for tests and support them whilst they are undergoing investigations.	Don't rush the explanation of next steps and the writing up of notes and any referral letter to the Community Learning Disability Team. If the person has not consented or lacks capacity, but you believe it is in their best interest. You can share information with this team if it is in the person's best interests.

	<p>NB: It is important that the team know exactly what tests the person is undergoing, the reason behind the tests and that cancer is being ruled out. It will be the same for any carers.</p> <p>Use the MCA, Best interests meeting forms on Remedy and Teamnet, Consider Involving an IMCA</p>	<p>NB: Very few people with a learning disability have a Power of Attorney regarding their health. This should be accepted and Best Interests applied when talking to family members, carers and the staff supporting them.</p>
<p><b>Giving written information</b></p>	<p>Consider the person's ability to understand generic information. Consider giving information in an 'Easy Read' format. Their carer/staff should receive the usual written information.</p> <p>Macmillan have excellent easy read cancer information  <a href="https://be.macmillan.org.uk/be/s-428-easy-read-titles.aspx">https://be.macmillan.org.uk/be/s-428-easy-read-titles.aspx</a></p>	<p>There is a range of easy read information on Remedy &amp; Teamnet for GP practices;  <a href="https://remedy.bnssgccg.nhs.uk/adults/cancer-support/lwbc-resources-for-gps/">https://remedy.bnssgccg.nhs.uk/adults/cancer-support/lwbc-resources-for-gps/</a>  <a href="https://teamnet.clarity.co.uk/Topics/ViewItem/90c338c2-0a08-4b60-a4bd-ac5300f10295">https://teamnet.clarity.co.uk/Topics/ViewItem/90c338c2-0a08-4b60-a4bd-ac5300f10295</a></p> <p>Also CRUK have an excellent resource for all aspects of cancer treatment  <a href="https://www.cancerresearchuk.org/about-cancer/coping/general-books-links-for-people-learning-disabilities">https://www.cancerresearchuk.org/about-cancer/coping/general-books-links-for-people-learning-disabilities</a></p>
<p><b>Patient Communication</b></p>		
<p><b>Results of tests</b></p>	<p>The results of the tests should be shared with the person in the most appropriate way:</p> <ul style="list-style-type: none"> <li>• to them directly – possibly in easy read format</li> <li>• to their recognised carer</li> <li>• to them and the Sirona Adult Learning Disability Health Service (CLDT) if they also work with the patient</li> </ul>	<p>Don't assume the person will be able to understand a test result by themselves, especially over the telephone.</p> <p>Don't only speak to the person if they lack capacity to consent to next steps. Always act in the person's best interests.</p>
<p><b>Planning a diagnosis discussion</b></p>	<p>Try to ensure the person will be accompanied by a carer or staff member to help support them with their diagnosis discussion. If they live independently the Sirona Adult Learning Disability Health Service (CLDT) may be able to support the person</p>	<p>Don't undertake this discussion with a person who is alone and whom you suspect doesn't have capacity to understand what is being said or make decisions about their care. Act in their best interest at all times.</p>
<p><b>Referral for further tests or back to GP</b></p>	<p>This should be communicated clearly to the person and their carer/ CLDT (if present), along with any further suspicions/ indications as to what the diagnosis may be.</p>	<p>The person may not be able to understand a test result by themselves or over the phone. You will likely need to speak to a family member or care staff so they have full information to support the</p>

		<p>person.</p> <p>If they live independently you may need to involve the Sirona Adult Learning Disability Health Service (CLDT) to reduce likelihood of Did Not Attend.</p>
<b>Covid-19 Precautions</b>	<p>Make sure all parties are aware of the precautions they need to take in order to attend appointments at the hospital and are prepared for these in advance. Consider whether you should make a referral to the Learning Disability Hospital Liaison Team to support the patient around this.</p>	<p>Don't assume people are used to seeing everyone in mask in a clinical environment. This could be frightening. Clear masks may be needed for lip reading or for reassurance. People may not be able to tolerate mask wearing so be ready with reasonable adjustments.</p>
<b>Consultant to patient communication</b>		
<p>All BNSSG hospitals – have a hospital passport for people with learning disabilities. This should be used for all hospital admissions and if the patient has one, a copy should be available on EMIS. Sometimes the person and their carers will have completed a paper version. You could ask them to bring that along to any appointments at the GP practice.</p>		
<b>Video consultations (impact of Covid-19)</b>	<p>Consider if face-to-face would be better and what reasonable adjustments may be required.</p> <p>Discuss with carers and Learning Disability Hospital Liaison Team.</p>	<p>Video consultations may not be successful. So take all the steps you can to ensure appropriate carer/ Learning Disability Hospital Liaison Team support is available to the patient, which includes help beforehand to attend their appointment at the designated time.</p>
<b>Diagnosis</b>	<p>The results of the tests should be shared with the person in the most appropriate way:</p> <ul style="list-style-type: none"> <li>• to them directly</li> <li>• to them and a recognised carer</li> <li>• to them, a recognised carer) and the Community Learning Disability Team if they also work with the person</li> </ul>	<p>Don't undertake this discussion with a person who is alone and who you suspect doesn't have capacity to understand what is being said or able to make decisions about their care. Act in their best interest at all times. Document MCA/BI meetings using the BNSSG forms on Remedy and involve an Independent Mental Capacity Advocate (IMCA) if necessary</p>
<b>Treatment planning or advanced care planning</b>	<p>Many people with a learning disability do not have a Power of Attorney regarding decisions about their health, although some may have a Deputy for Health &amp; Welfare (Court of Protection). Mental Capacity Assessments and Best</p>	<p>Don't undertake this discussion with a person who is alone and who you suspect doesn't have capacity to understand what is being said or able to make decisions about their care. Act in their best</p>

	<p>Interests meetings/discussions should be applied when talking to family members, carers and the Sirona Adult Learning Disability Health Service, if person lacks capacity. Family members cannot consent on the person's behalf (unless they have a deputyship), neither can paid care staff.</p>	<p>interest at all times. Document MCA and BI meetings using the BNSSG forms and involve an Independent Mental Capacity Advocate. (IMCA)</p>
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**Good practice for hospital admission, treatment and discharge of people with a learning disability:**

Stage in Pathway	Helpful action	Not so helpful
<p><b>Operations/ Invasive procedures</b></p>	<p>Consider involving the hospital Learning Disability Liaison Teams in preparing a person for a surgical or invasive procedure. Make sure you read their referral and notes fully to understand any anxieties or particular needs the person has (e.g. reasonable adjustments). This includes reading their Hospital Passport.</p>	<p>Don't Assume the person is not very nervous and will not need extra support in the form of a carer or hospital <b>Learning Disability Liaison Team</b>.</p> <p><b>Southmead;</b>  <a href="mailto:learningdisabilities@nbt.nhs.uk">learningdisabilities@nbt.nhs.uk</a>.</p> <p><b>UHBW</b>  <a href="mailto:learningdisabilities@uhbw.nhs.uk">learningdisabilities@uhbw.nhs.uk</a></p>
<p><b>Radiotherapy/ Chemotherapy</b></p>	<p>Ensure the person and everyone involved supporting the person is aware of the schedules, time and equipment that will be used. Make sure the person is accompanied, if that is what is required in their best interests. Liaise closely with the hospital <b>Learning Disability Liaison Team</b>.</p>	<p>Don't expect this process to run to normal time frames. The person may need more extra time. The <b>Learning Disability Liaison Team</b> are very experienced at making reasonable adjustments &amp; providing support to the person</p>
<p><b>Discharge</b></p>	<p>Make sure that the person and everyone involved in supporting the person is involved in discharge planning and the patient feels ready to move on to the next stage. Be prepared to give this process more of your time to get it right.</p>	<p>Sometimes next of kin are not involved in the person's day-to-day care, especially if the person does not live with family. Discharge information should go to GP, next of kin AND residential care staff.</p>
<p><b>Follow-up</b></p>	<p>Make sure that the person and everyone involved in supporting the person knows the regime and what will be involved if it involves a test. And repeat the process as for the navigator (above).</p>	<p>Sometimes next of kin are not involved in the person's day-to-day care, especially if the person does not live with family. Discharge information should go to GP, NoK AND care provider staff.</p>

<p><b>Palliative care</b></p>	<p>Explain next steps clearly and emphasise key parts of the next stage. Make sure that the person and any carers of support staff feel able to ask questions. Consider what extra support the person will need, talking to their carer, hospital Learning Disability Liaison Team and GP. All BNSSG practices have a GP lead for Learning Disabilities who can advise and support the patient's own GP. Make sure the Treatment Escalation Plan (TEP)/RESPECT form is written correctly. Where possible it is helpful to write this in an easy read format.</p>	<p>Macmillan have excellent end of life, palliative care easy read resources; <a href="https://be.macmillan.org.uk/be/s-853-end-of-life-and-bereavement.aspx">https://be.macmillan.org.uk/be/s-853-end-of-life-and-bereavement.aspx</a></p>
<p><b><u>Useful Contacts:</u></b></p> <p><b><u>Sirona Adult Learning Disability Health Service</u></b> – (previously known as Community Learning Disability Team) Advice Line: 0300 124 5888 Email: <a href="mailto:sirona.bcltdadvice@nhs.net">sirona.bcltdadvice@nhs.net</a></p> <p><b><u>Southmead Hospital:</u></b> Learning Disability &amp; Autism Hospital Liaison Team Tel: 0117 4141239 Email: <a href="mailto:learningdisabilities@nbt.nhs.uk">learningdisabilities@nbt.nhs.uk</a> <a href="https://www.nbt.nhs.uk/patients-carers/coming-hospital/learning-disability-nurses">https://www.nbt.nhs.uk/patients-carers/coming-hospital/learning-disability-nurses</a></p> <p><b><u>Bristol Royal Infirmary and Weston General Hospital:</u></b> Learning Disability &amp; Autism Hospital Liaison Team Tel: 0117 342 1707 / Bleep 6593 Email: <a href="mailto:learningdisabilities@uhbw.nhs.uk">learningdisabilities@uhbw.nhs.uk</a>  <a href="http://www.uhbristol.nhs.uk/patients-and-visitors/support-for-patients/patients-with-a-learning-disability-or-autistic-spectrum-disorder-(asc)/">http://www.uhbristol.nhs.uk/patients-and-visitors/support-for-patients/patients-with-a-learning-disability-or-autistic-spectrum-disorder-(asc)/</a></p>		
<p><b><u>BNSSG ICB</u></b> Georgia Diebel Senior Primary Care Cancer Facilitator (Early Diagnosis) Tel: 0117 900 2222 Email: <a href="mailto:georgia.diebel1@nhs.net">georgia.diebel1@nhs.net</a></p>	<p><b><u>Cancer lead GP BNSSG ICB (Thursdays)</u></b> Dr Glenda Beard Email: <a href="mailto:glenda.beard2@nhs.net">glenda.beard2@nhs.net</a></p>	