

Identifying and managing deterioration in people with learning disabilities



#### Helping the session run smoothly



Stay on mute unless you are speaking Cameras off unless speaking



Use the chat for your ideas or questions - we'll be asking some questions for you to take part in



Use 'Hands Up' if you have a question



We can't see you, but you'll see the people speaking



More ... Add your name, workplace & email in chat

#### Welcome





#### What is STOP LOOK CARE?



#### **STOP LOOK CARE**

#### **Training session objectives**

- How the Stop Look Care approach and booklet works
- Why different aspects of observation and care are important, particularly in supporting those with learning disabilities
- How Stop Look Care can help you spot deterioration
- How to escalate what you are observing using the SBARD tool



#### **STOP LOOK CARE - How does it work?**

- Stop Look Care covers a variety of topics of health and wellbeing that complement the Care Certificate
- Each page of the STOP LOOK CARE booklet gives an overview of the topic, what good care looks like and how to support the person with learning disabilities you care for or support in these areas
- Stop Look Care uses a traffic light system to help you identify change and to take action
  - GREEN ACTION = None
  - ORANGE ACTION = Monitor and Document
  - RED ACTION = REFER Seek further support and advice

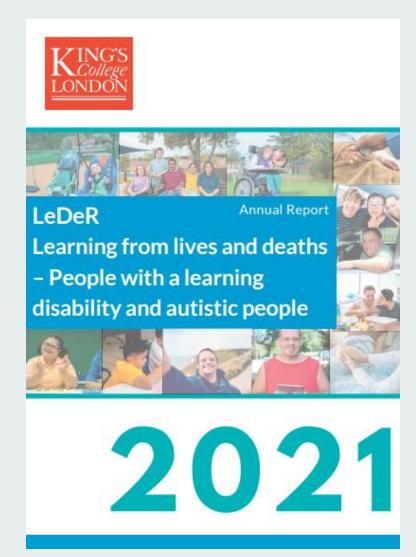
#### **STOP LOOK CARE - What does it include?**



- SBARD
- Basic Life Support
- SEPSIS screening tool
- UTI
  - Prevention
  - Dehydration
  - fluids
- Nutrition
- Swallowing
- Mouth care
- Skin
  - Prevention of pressure damage
  - Excoriation tool
- Mobility and falls prevention

- Frailty
- Breathing
- Continence
- Diabetes
- Medication
- Adult social care
- MCA
- Adult safeguarding
- Mental health
- Dementia
- Delirium
- Pain
- Advance care planning
- Care of the dying







2021 LeDeR report into the avoidable deaths of people with learning disabilities (kcl.ac.uk)

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#### **STOP LOOK CARE**

LeDeR has identified that the signs of physical health deterioration in people with learning disabilities are not well recognised. You know the person best. The Stop Look Care booklet helps you formulate the different pieces of the puzzle to ensure that a clinician can better identify and treat illness. STOP LOOK CARE covers the fundamentals of health care and supports you to do the following:

- Understand why different aspects of observation and care are important
- Supports you in what to look for and identify change or deterioration
- · Identify what actions to take if you suspect deterioration

#### Learning from LeDeR

#### The five most frequently reported long term health conditions 2021

- 1. Epilepsy
- 2. Cardiovascular conditions
- 3. Mental health conditions high prevalence of schizophrenia
- 4. Sensory impairment prevalence in pwld 33% visual imp, 40% hearing imp
- 5. Dysphagia 40% with dysphagia experience recurrent respiratory tract infections

**Dementia** – higher prevalence, onset 30 – 40 years earlier

Oral health – one third adults have unhealthy teeth & gums

#### The top 5 grouped causes of death 2021

- 1. COVID-19
- 2. Diseases of the Circulatory System
- 3. Diseases of the Respiratory System
- 4. Cancers deaths from cancer lower than general population and higher rates of gastrointestinal cancer
- 5. Diseases of the Nervous System

**Constipation** and **Sepsis** were also recorded as causes of death reported to LeDeR

## **Key areas from STOP LOOK CARE booklet**

- Page 6 Sepsis
- Pages 9-13 UTIs/Hydration
- Pages 34-37 Continence
- Page 15 Nutrition
- Pages 20-21 Mouthcare
- Page 50 Pain
- Page 52 Advance Care Planning
- Page 57 Care standards

#### **But why? What are the Barriers?**

Communication

Diagnostic overshadowing

**Lack of Knowledge** 

Lack of reasonable adjustments

Poor application of Mental Capacity
Act

Lower uptake of screening

**Discrimination** 



# How do people communicate if they are unwell? How do you know if someone is unwell?

**Chat Box Discussion** 



## Spotting the softer signs of deterioration in people with a learning disability

NHS England and NHS Improvement have also worked with the lead sepsis nurse and lead learning disability nurse at Sherwood Forest Hospitals NHS Foundation Trust to develop a training film. It supports health and care professionals, and carers, to spot the softer signs of deterioration in people with a learning disability. The film features an actor with autism and a learning disability.

https://www.youtube.com/watch?v=CflZRfFZj8c&feature=youtu.be



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#### **Examples of "Soft Signs"**

Soft Signs can be related to many things including:

#### **Changes in physical presentations**

- being short of breath
- not passing much urine
- being hot, cold or clammy to touch
- being unsteady while walking

#### **Changes in mental state**

- having new or worse confusion
- feeling more anxious or agitated
- being more withdrawn than normal

#### Changes in behaviour or ability

- increased tiredness
- altered sleep pattern
- reduced inhibitions
- being very restless or hyperactive

SLC – Page 5 tips for recognising a rapidly deteriorating person

**SLC** – Page 6/7 Sepsis



### SBARD Getting your Message Across



SBARD tool (SLC - page 4-5)



#### Telling someone you're worried (SBARD)



#### SBARD TOOL Situation Background Assessment Recommendation Decision

S	Situation	I am a carer (Name) working for (Organisation) Tel: I am calling about Mr / Mrs Name; DoB: NHS No: Address I am calling because I am concerned that / I am unsure about / I need advice	
В	Background	Their normal condition is (e.g. alert / drowsy / confused / self-caring) How has this changed? Their relevant history includes (e.g. asthma, dementia, ischaemic heart disease) Current medications include (e.g. x, y, z)	
A	Assessment	I have found that he / she is (e.g. struggling to breathe / walk / has pain / has injured / confused) Vital signs if equipment available (e.g. blood sugar, temperature, blood pressure, pulse) I think the problem is / may be OR I don't know what's wrong but I'm really worried	
R	Recommendation	I now need your assistance I would like you to visit the resident (when is it urgent or routine?) I would like your advice as to what to do next / in the meantime	
D	Decision	We have agreed that the following decisions were made and the following action(s) that will now be taken I will record the decision and action in the service users/patients record or communication sheet Record decision and action where appropriate	

#### **RESTORE2 Mini**

**The AHSN Network** 



#### Introducing



Recognise early soft-signs, Take observations, Respond, Escalate



Geoff Cooper Wessex AHSN



Dr Matt Inada Kim National Sepsis Lead



Matthew Richardson West Hampshire CCG





#### **RESTORE2 Mini**



#### Signs someone may be unwell and what should I do?

#### Ask the person you support – how are you?

Does the person show any of the following 'soft signs' of deterioration?

- Increasing breathlessness, chestiness or cough/sputum
- Change in usual drinking / diet habits
- = A shivery fever feel hot or cold to touch
- = Reduced mobility 'off legs' / less co-ordinated or muscle pain
- New or increased confusion / agitation / anxiety / pain
- Changes to usual level of alertness / consciousness / sleeping more or less
- Extreme tiredness or dizziness
- = 'Can't pee' or 'no pee', change in pee appearance
- = Diarrhoea, vomiting, dehydration

Any **concerns** from the person / family or carers that the person is not as well as normal.

If purple signs are present, think possible COVID-19.

If YES to one or more of these triggers - take action!

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#### Get your message across

Raise the alert. If you are a family carer or friend and are worried about the person you support talk to their nurse or GP. In an emergency you may need to call NHS 111 or 999. Support workers or home carers can also do this or consult a colleague or manager. Try using the SBARD Structured Communication Tool (below) to support reporting your concerns.

D.O.B.

S	<b>Situation</b> e.g. what's happened? How are they?	Key prompts / decisions	
В	<b>Background</b> e.g. what is their normal, how have they changed?		
A	Assessment e.g. what have you observed / done?		
R	Recommendation 'I need you to'		
D	<b>Decision</b> what have you agreed?		
Name of completi		Signature:	

If you are worried about the person, don't just think about it, seek advice.

CSS2291 NHS Creative 1/2021





#### **Case Studies**



## STOP LOOK CARE CASE STUDY Eileen

Eileen lives in supported living with three peers. Staff are available throughout the day and night. Some of the staff have supported her for many years and know her really well.

Eileen has a severe learning disability and shows you what she wants by taking you to it. She particularly loves tea but is drinking less. She also has a severe scoliosis which over time has resulted in her developing chest problems.

Eileen usually eats a good diet but has recently lost some weight. When Eileen is in pain she may pull at her hair, which she is doing more often. She has recently taken longer to open her bowels and fractured her wrist after a fall.

#### Mouthcare – pages 20 - 21

Good oral health care enables people to take a normal diet without difficulty. Carers play an important role in supporting people to maintain good oral health. Carers are ideally placed to monitor changes in individual's mouths and refer on as appropriate.

Gum disease and poor oral health may increase the risk of all kinds of other health complications, including:

- Lack of appetite
- Malnutrition
- Heart disease
- Pneumonia



Mouth is healthy, clean and moist No further action required

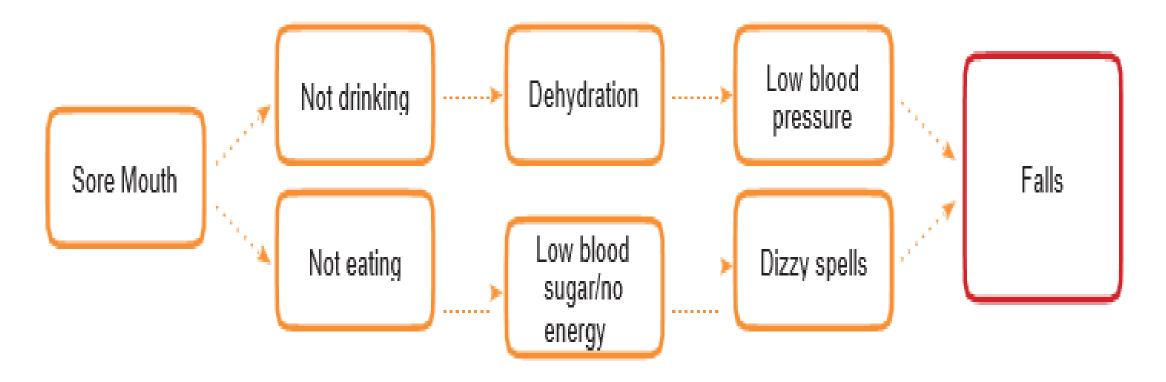
Mouth is dry, food and bits remain around teeth Monitor, document and support individual with mouth care if needed and explain the importance of mouth care to the individual

Mouth is inflamed, dry and sore or ulcerated Seek additional support on day identified from GP, or their own Dentist and document

#### **STOP LOOK CARE**

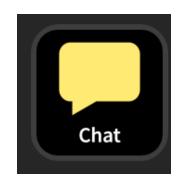
#### How Stop Look Care can help you spot deterioration

Remember that different conditions or different aspects of poor health can impact on another area of the body.



#### Guidance on Supporting Mouth-Care

Explain how you are going to support them, as some people can feel anxious. Encouraging individuals to look in the mirror whilst being supported will enable them to see what is happening. It can be easier for the carer to stand slightly behind, or to the side, when supporting individuals with oral health care	<ul> <li>Some individuals gums may bleed when brushing, this is a sign that their gums are unhealthy. The only way to improve gum condition is to gently brush the bacteria away</li> <li>Teeth should be brushed in a circular motion with a small amount 'pea sized' toothpaste</li> </ul>	<ul> <li>Ensure dentures are labeled in a denture pot, as these can go missing when individuals are admitted to hospital</li> <li>Loss of dentures may cause great distress and can be expensive and time consuming</li> </ul>
<ul> <li>Ensure the person is comfortable and ensure that you are not rushed.</li> <li>Remember you may not be able to support brushing the person's whole mouth in one go</li> </ul>	<ul> <li>Encourage people to spit out after brushing and not to rinse</li> <li>It is better to leave a little toothpaste residue in the mouth to maintain fluoride concentration levels</li> </ul>	<ul> <li>Support individuals with false teeth to clean them daily</li> <li>Dentures should be removed at night and soaked in plain water</li> </ul>
<ul> <li>Support the person twice a day to clean their teeth</li> <li>Replace the tooth brush every three months or sooner if required</li> </ul>	<ul> <li>The frequency and amount of sugary food and drink should be reduced and where possible, kept to mealtimes</li> </ul>	Ensure when the person's dentures are removed they do not have any residual food left in their mouth
<ul> <li>Dentures which do not fit well can affect eating, drinking and speaking and can be uncomfortable</li> </ul>	Frequent oral health care is important for those who are unable to take any food or drink orally. It is important to minimise oral bacteria that might be aspirated, as well as optimising oral comfort	https://www.dentalhealth.org/tell-me- about/topic/caring-for-teeth/caring-for-my- teeth



#### **Question?**

What might you do to help someone who is resistant to mouth care to have good oral hygiene?



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## STOP LOOK CARE CASE STUDY Ernie

Ernie - middle aged gentleman with moderate learning disabilities.

He has always had difficulties with constipation due to having Hirschsprung's disease (affects nerve supply to the bowel) and has regular prescribed medication for this.

Generally, a very happy gentleman however recently there have been changes in that he has not been eating or drinking which is unusual for him.



What would you do next?

 One evening Ernie started vomiting and had explosive diarrhea

 He was clutching his stomach and indicating to staff that he was in pain



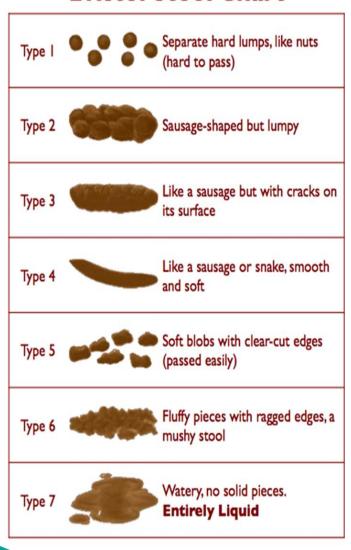
#### What happened next...

 Ernie was admitted to A & E where he was scanned and found to have a severely impacted bowel, which required surgical intervention and unfortunately had to have part of his bowel removed as it was damaged

 Fortunately this did have a good outcome and Ernie recovered well from the operation. He was able to return home after two weeks in hospital

#### **Continence - Pages 36-37**

#### **Bristol Stool Chart**



Bowels normal for individual No further action required

Change in bowel habit, constipation without pain, make a routine referral to GP.

Monitor, document and support individual with continence care if needed.

If stools are very dark (black) or very pale encourage the person to speak with their GP.

Some medications can change the colour of stools, this can be discussed with a pharmacist.



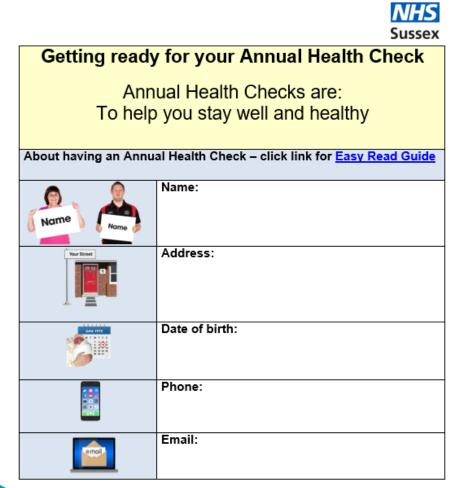
## Supporting Good Health in Adults with a Learning Disability



#### Things we can do to support good health

- ✓ Check that people are on the GP Learning Disability Register
- ✓ Arrange an Annual Health Check at their GP surgery for any person who has not had one or is overdue for one
- ✓ Support people to complete the Getting Ready for Your Annual Health Check booklet
- ✓ Support people to complete the My Care Passport
- ✓ Book an appointment with the GP to review a person's medications
- ✓ Check if the person/people you support are up to date with their cancer screening
- ✓ Check that people are up to date with Vaccination programmes (Flu / Covid).
- ✓ Check the person has been given a Health Action Plan and actions on the plan are being carried out

#### Sussex Annual Health Check Resources



- Getting Ready for your Annual Health Check
- Guide for Carers
- Easy Read resources

https://www.sussex.ics.nhs.uk/your-care/local-nhs-services/support-for-people-with-a-learning-disability/

#### **My Care Passport**



Have people you support got an up-to-date My Care Passport?

You can download it from this link





## STOP LOOK CARE Recap



# **STOP LOOK CARE – Care Standards**

# Benefits to you, your service and those you care for

- ✓ The health inequalities people with learning disabilities are known to face can be reduced
- ✓ Staff are empowered, trained and supported to recognise deterioration in health and wellbeing and make the right decision when this happens
- ✓ Staff have increased confidence to request care that evidence shows is required
- Supports the development of relationships with health services to better understand each other's role
- ✓ Supports CQC preparedness and achievement
- Supports the development and management of workforce with the potential for a positive effect on recruitment and retention

# **STOP LOOK CARE**What have we learnt today?

- How to reduce the health inequalities people with learning disabilities are known to face by getting quick and good health care
- How the Stop Look Care approach and booklet works
- Why different aspects of observation and care are important
- How can Stop Look Care help you spot deterioration
- How to escalate what you are observing using the RESTORE 2 mini tool and SBARD





# Resources



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# **STOP LOOK CARE - Resources**



### **Stop Look Care Booklet**

https://www.sussex.ics.nhs.uk/wp-content/uploads/2021/02/240673-Care-Booklet-Final.pdf

### **Videos**

https://www.sussex.ics.nhs.uk/our-vision/priorities-and-programmes/supporting-carers/stop-look-care-training/

# **Manage - RESTORE2 Mini**

**RESTORE2 - The Deterioration and Escalation Tool for Care** 

ings. - Yo



### Signs someone may be unwell and what should I do?

### Ask the person you support - how are you? Does the person show any of the following 'soft signs' of deterioration? Increasing breathlessness, chestiness or cough/sputum Change in usual drinking / diet habits = A shivery fever - feel hot or cold to touch = Reduced mobility - 'off legs' / less co-ordinated or muscle pain New or increased confusion / agitation / anxiety / pain = Changes to usual level of alertness / consciousness / sleeping more or less Extreme tiredness or dizziness "Can't pee' or 'no pee', change in pee appearance Diarrhoea, vomiting, dehydration Any **concerns** from the person / family or carers that the person is not as well as normal. If purple signs are present, think possible COVID-19.

If YES to one or more of these triggers - take action!

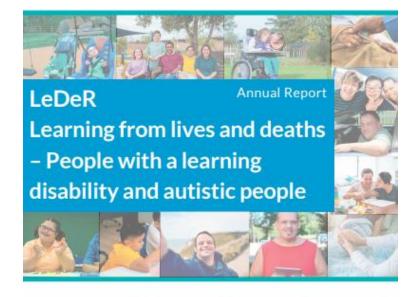
### Get your message across Client name: NHS No. D.O.B. Raise the alert. If you are a family carer or friend and are worried about

the person you support talk to their nurse or GP. In an emergency you may need to call NHS 111 or 999. Support workers or home carers can also do this or consult a colleague or manager. Try using the SBARD Structured

S	<b>Situation</b> e.g. what's happened? How are they?	Key prompts / decisions
В	<b>Background</b> e.g. what is their normal, how have they changed?	
A	Assessment e.g. what have you observed / done?	
R	Recommendation 'I need you to'	
D	<b>Decision</b> what have you agreed?	
iame of person ompleting:		Signature:
loday's	date:	

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2021

2021 LeDeR report into the avoidable deaths of people with learning disabilities (kcl.ac.uk)

LeDeR - Action from learning reports

Learning disability and autism - Sussex Health and Care (ics.nhs.uk)

# **HEE - Training Videos**

- Introduction to sepsis and serious illness
- Preventing the spread of infection
- Soft signs of deterioration
- Measuring the respiratory rate
- Measuring oxygen saturation
- Measuring blood pressure
- Measuring the heart rate
- Measuring level of alertness
- How to measure temperature
- SBARD Structured communication and escalation
- Treatment escalation plans and resuscitation
- Recognising deterioration in people with a learning disability
- How to use your pulse oximeter and Covid-19 diary

Health Education England Youtube website. Better health and care for all

# **Blood Pressure monitoring**

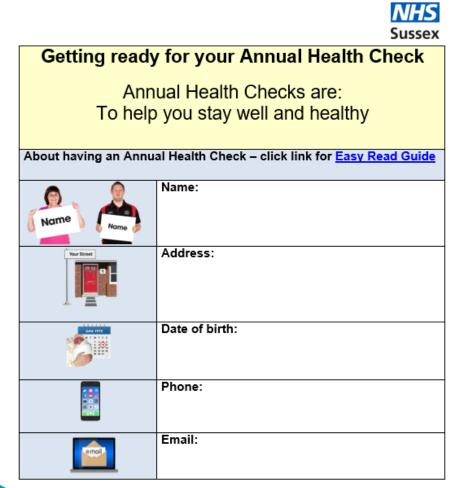


<u>Understand Your Blood Pressure.pdf</u> (ics.nhs.uk)

**Easy Read information** 

Measuring blood pressure Youtube video

### Sussex Annual Health Check Resources



- Getting Ready for your Annual Health Check
- Guide for Carers
- Easy Read resources

https://www.sussex.ics.nhs.uk/your-care/local-nhs-services/support-for-people-with-a-learning-disability/

# **My Care Passport**



Have people you support got an up-to-date My Care Passport?

https://www.bsuh.nhs.uk/your-visit/help-and-support/learning-disabilities/

My Care Passport download link

vtS

### Disability



Distress Assessment Tool				
Client's name:				
DoB:	Gender:			
Unit/ward:	NHS No:			
Your name:	Date completed:			
Names of others who helped complete this form:				
Intended to help identify distress cues in people who because of cognitive impairment or physical illness have sever limited communication.				
Designed to describe a person's usual content cues, thus enabling distress cues to be identified more clearly.				
NOT a scoring tool. It documents what many staff have done instinctively for many years thus providing a record again which subtle changes can be compared. This information can be transferred with the client or patient to any environment				
Only the first step. Once distress has been identified the usual clinical decisions have to be made by professionals.				
Meant to help you and your client or patient. It gives you more confidence in the observation skills you already ha which in turn will help you improve the care of your client or patient.				
INSTRUCTIONS FOR USING DISDAT ARE ON THE BACK PAGE				
SUMMARY OF SIGNS AND BEHAVIOURS				
Appearance when CONTENT	Appearance when DISTRESSED			
Face Eyes	Face Eyes			
Tongue/jaw	Tongue/jaw			
Skin	Skin			
Vocal signs when CONTENT	Vocal signs when DISTRESSED			
Sounds	Sounds			
Speech	Speech			
	)()			
Habits and mannerisms when CONTENT	(Habits and mannerisms when DISTRESSED)			
Habits	Habits			
Mannerisms	Mannerisms			
Comfortable distance	Comfortable distance			
Posture & observations when CONTENT Posture & observations when DISTRESSE				
Posture	Posture			
@L	Olement			

Known triggers of distress (write here any actions or situations that usually cause or worsen distress)

# **DisDat**

Disability distress assessment tool baseline assessment and what may change and how if someone with very limited verbal communication is in pain or distress.



Stopping over medication of people with a learning disability, autism or both

Stopping over medication of people with a learning disability, autism or both (STOMP)

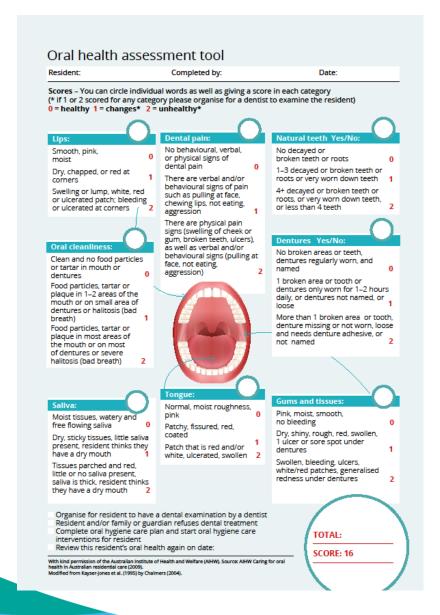
https://www.england.nhs.uk/wp-content/uploads/2018/02/stomp-easy-read-leaflet.pdf



Preparing to visit a Doctor to talk about psychotropic medication



# **Oral Health Care**



**STOP LOOK CARE** guidance on oral health care, pages 20 - 21

Improving-oral-health-for-adults-in-care-homes guidance on how to support people to have healthy teeth and gums, and includes an oral hygiene chart and oral care assessment.

PHE Guidance on Oral care and people with learning disabilities good oral care.

# **Oral Health Promotion Teams**

### **Brighton & Hove**

Specialist Dental Care Service Oral Health Promotion Team

Email: sc-tr.ohp@nhs.net

### **West Sussex**

Special Care Dental Services (SCDS) (sussexcommunity.nhs.uk)

### **East Sussex**

Special Care Dental Service

Tel: 0300 131 4542

Email: esht.communitydentalservice@nhs.net

Special Care Dental Service – East

Sussex Healthcare NHS Trust

# Constipation and people with a learning disability



- Constipation leaflet easy read
- https://www.england.nhs.uk/publicati on/constipation-learning-disabilityresources/
- Constipation leaflet Information for families and carers
- Constipation leaflet Information for health care professionals
- Preventing people with LD Dying from Constipation – Webinar

# Flu / Covid vaccination



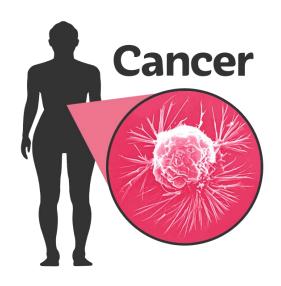
- Check people are up to date with Vaccination Programmes
- Support people to ask for reasonable adjustments
- Can the Flu vaccination be done at the Annual Health Check?

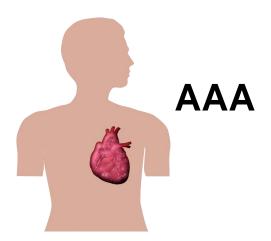
Vaccination: easy read leaflets

Flu https://www.gov.uk/government/publications/flu-leaflet-for-people-with-learning-disability

Covid <a href="https://www.gov.uk/government/publications/covid-19-vaccination-easy-read-resources">https://www.gov.uk/government/publications/covid-19-vaccination-easy-read-resources</a>

# **Screening Programmes**





- Check to see if people are up to date with screening programmes
- Encourage people to take part in screening programmes

### An easy guide to cervical screening:

https://www.gov.uk/government/publications/cervical-screening-easy-read-guide

### An easy guide to breast screening:

https://www.gov.uk/government/publications/breast-screening-information-for-women-with-learning-disabilities

### How to look after my balls:

https://www.easyhealth.org.uk/wp-content/uploads/2020/03/How-to-look-after-my-balls.pdf

### **Abdominal Aortic Aneurysm or AAA screening:**

https://www.easyhealth.org.uk/wp-content/uploads/2020/03/Abdominal-Aortic-Aneurysm-AAA-Screening.pdf

### **Bowel Screening an Easy Guide:**

https://www.gov.uk/government/publications/bowel-cancer-screening-easy-guide

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### https://www.easyhealth.org.uk/

Large collection of easy read leaflets that have been developed by a variety of organisations



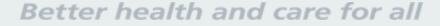
http://www.easyontheileeds.nhs.uk/all/

Easy read image bank



# Contacts





# **Health Facilitation Contacts**

**Brighton & Hove** 

Tel: 01273 296507

Mobile: 07517131341

**Email: Jane.Viner@brighton-**

hove.gov.uk

West Sussex

Tel: 01403 620438

Email: sc-tr.ldhf-horsham@nhs.net

**East Sussex** 

**Email:** 

sxicb.ldahfteastsussex@nhs.net

Sussex ICB

**Learning Disability Annual Health** 

**Check enquiries** 

**Email:** 

sxicb.learningdisabilityahc@nhs.net





Thank you



### **Any questions?**



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