



Self Advocacy Toolkit

Your Rights

Be treated with dignity, respect, and compassion.

01

Be seen promptly, especially during pain crises.

02

Receive pain relief within 30 minutes in A&E (NHS England Sickle Cell Care Standard).

03

Be involved in decisions about your care.

04

Access a second opinion.

05

When using Public Services, You Have The Right To

Request culturally appropriate care.

06

Use an advocate or support person.

07

Access interpreting services if English isn't your first language.

08

Complain if your care falls below standard.

09

you are entitled to a medical ID card that you can present at hospital

10

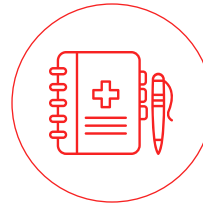
Legal Basis: NHS Constitution, Equality Act 2010, and Human Rights Act 1998

Self-Advocacy Tools: **How to Speak Up**



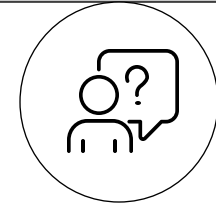
Use the “I” Statement Formula

- “I am in a lot of pain right now. I need pain relief urgently.”
- “I do not feel heard. Please include me in decisions about my care.”
- "I would like access to an advocate"



Keep a Journal

- Track appointments and document all interactions by following up with an email. Use the companies generic email address if you have no access to a direct email.
- Bring your journal to appointments to advocate for consistent care.



Pre-planning

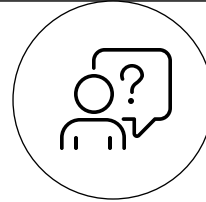
- Before you attend an appointment of any kind, write down a list of questions that will help you gain clarity and bring them to the appointment.
- Contact an advocacy service for any advice on what questions to ask.

Self-Advocacy Tools: **How to Speak Up**



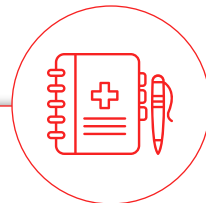
Pre-planning

- Contact the public service you are using and ask if they can please share any guidance or verbally explain their internal client process. This is so you can be clear about your rights and what to expect throughout their client process.



Ask Questions Like

- “What are my options?”
- **Can you please explain slowly and clearly so that I can understand?**
- “Can I speak with a specialist?”
- “Can this decision be reviewed by a senior ?”



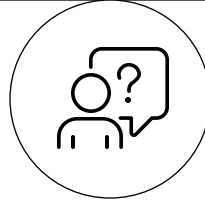
Be clear

- Relay or summarise what you have been told in the appointment and ask the public servant to confirm whether you have understood correctly.

Self-Advocacy Tools: **How to Speak Up**

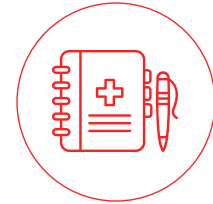
Be specific

- Ask the public service representative to **AVOID** the use of internal jargon or acronyms.
- Ask them to specify dates and time ranges. For eg, if they say someone will contact you, ask them for a specific date or time range. Document this and follow up.
- Ask for the name of the person dealing with your query or case for reference.



Let them know about your disability

- If you have a disability for e.g, you are dyslexic and need specialist care or adjustments, please let services know so that they can accommodate for you.



Store information

- Storing a trail of information is important
- You can use an app or 'Notes' on your phone to store the information. You can add a password to keep the info confidential. Contact your local Currys store or phone provider to help you.

Self-Advocacy Tools: **How to support yourself**

Time management

- Set reminders for appointments in your phone calendar. You can also use google calendar.
- Try to plan ahead and give yourself enough time to regulate and process information. Do not feel rushed to respond in the moment. Kindly explain that you may need time before responding.
- Give yourself enough time between meetings or appointments.

Communication

- Communication will be your best tool. YOU, get to plan your schedule. Be realistic with time-frames and with how much you can manage.
- You are not alone. Know when to ask for help from experts and Advisors.
- Communicate anything that you are still unclear about and seek further guidance.

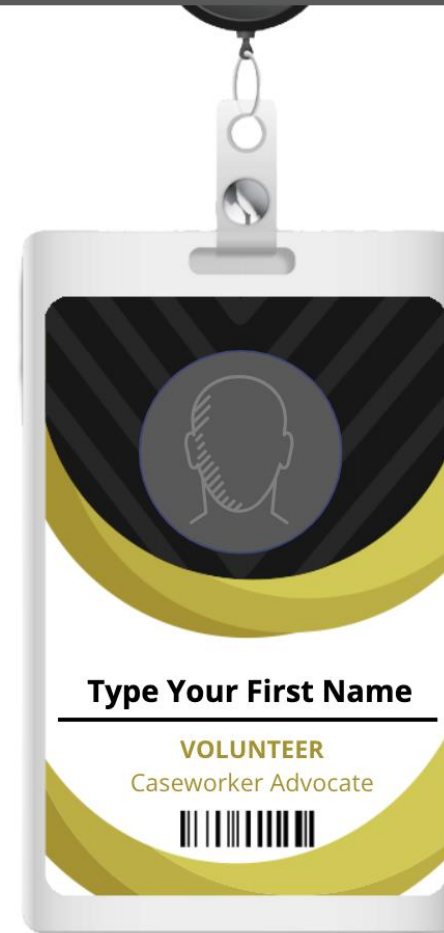
Look after you first

- There are mental health services available but, also remember to try and create a healthy routine if possible.
- Ensure you are getting enough sleep. If you are struggling with sleep try to identify why. Visit your doctor or try natural remedies.
- Remember to eat and stay hydrated. Do not underestimate the impact of everyday habits.

Complete our human rights module [Human Rights Module BHSS](#)

**BLACK
HERITAGE
SUPPORT
SERVICE**

VOLUNTEER TRAINING
Advocacy Caseworkers



START

NHS Services You Can Use: **Primary & Emergency Care**

If possible, register with a recommended **GP**.

Visit **A&E** for pain crises, but bring your care plan if you have one.

Primary & Emergency Care

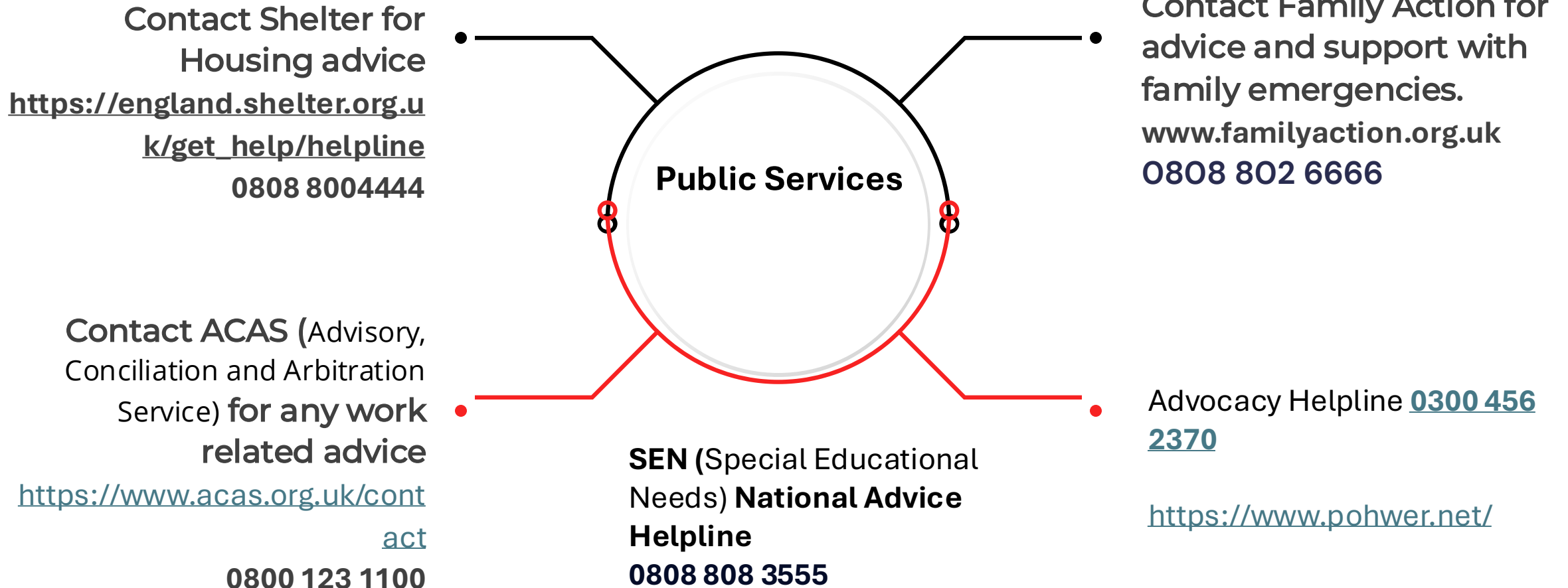
Use **111** when you need advice but it's not an emergency.

You can visit your pharmacy to treat several conditions.

Click the link to read about the new Pharmacy Scheme

[Pharmacy Scheme](#)

Public Services You Can Use



Specialist Services

You have the right to request an interpreter/advocate and to have documentation explained to you if it is not clear.

Depending on the service provider, you may also have access psychological support, pain management services, and counselling.

Template Letters & Scripts: **Sample Complaint Letter**



Complaint letter Example

Before complaining to an Ombudsman (regulatory service) You will usually need to go through an internal organisations formal complaint procedure.

"I am writing to express concern about the care I received on [date] at [location]. Despite presenting relevant information and following instructions, I was ignored by staff members. This caused unnecessary suffering and falls short of (company) guidelines. I would like an investigation and a formal response."

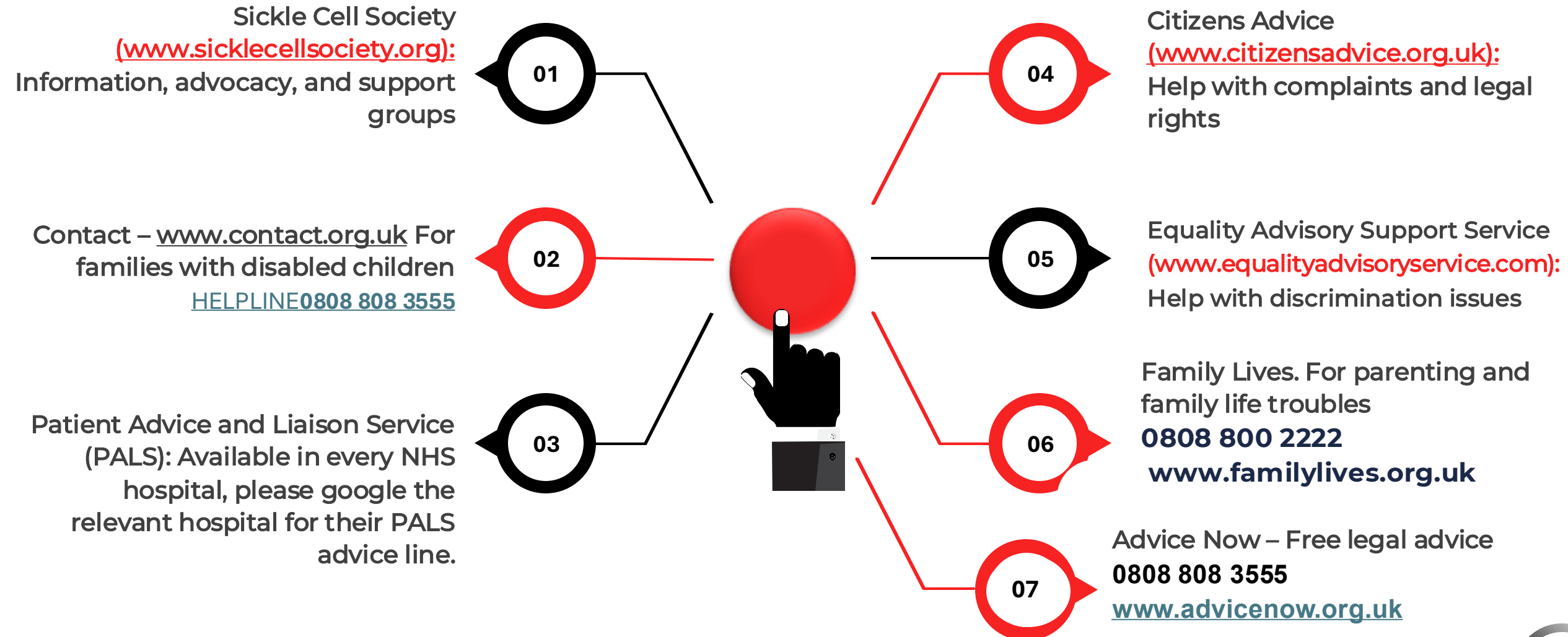


EG Script for A&E Visit Example

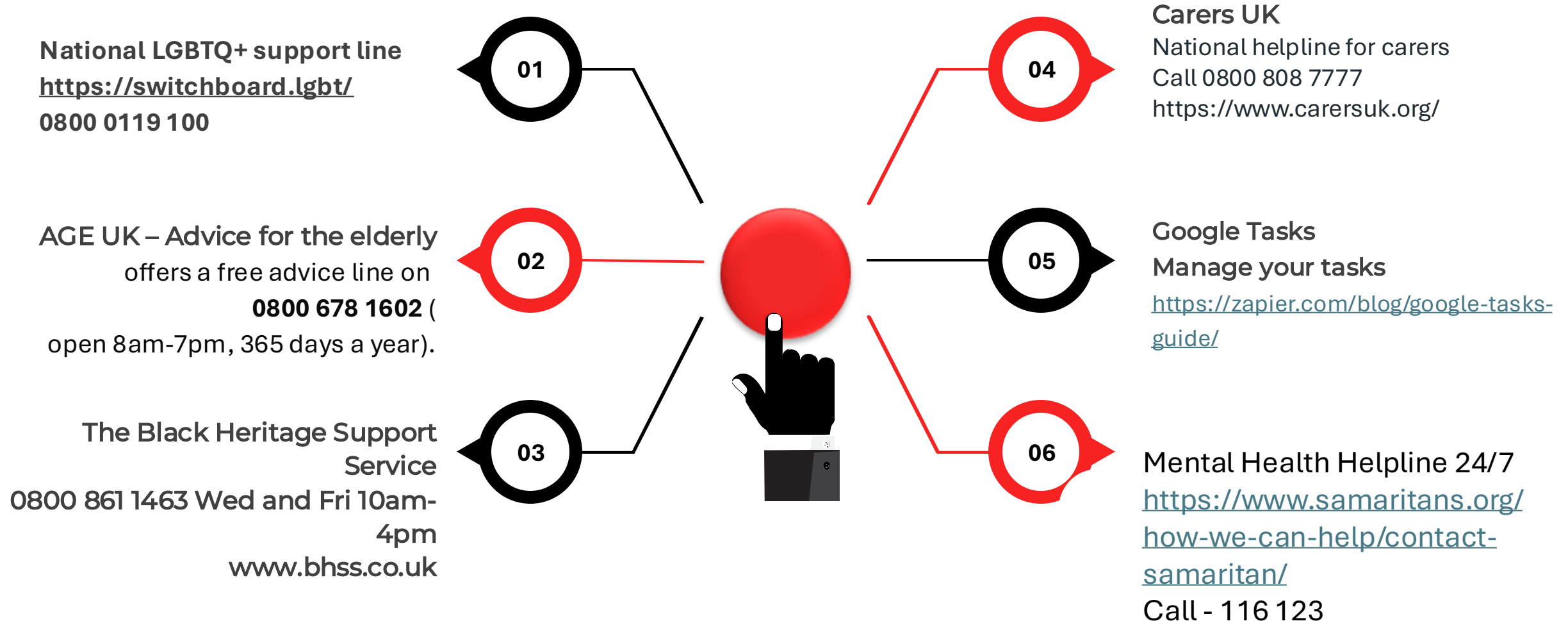
"I have (disorder). I'm experiencing a pain crisis. I need urgent pain relief within 30 minutes, per NHS guidelines.

Please refer to my care plan or contact my dedicated care team."

Getting Support



Getting Support





Your Rights, Your Voice: **Final Words**

You are not alone. Whether you're facing bias, being denied timely care, or just trying to understand how to navigate the system, this toolkit is your starting point. Don't be afraid to speak up, document everything, and seek support.

You have the right to be seen, heard, and cared for properly, no matter your background.

We hope this was helpful. If
you would like to contact us,

Please go to www.bhss.co.uk

The logo for the Black Heritage Support Service, featuring the words "BLACK", "HERITAGE", "SUPPORT", and "SERVICE" stacked vertically in a bold, white, sans-serif font with a black outline, all contained within a white circle with a red border.

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