

INTRODUCTION TO ADVOCACY

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WHY IS ADVOCACY IMPORTANT FOR SICKLE CELL?

- Inequalities in healthcare access and provision
- Access to welfare and benefits
- Stigma and lack of understanding of sickle cell in wider communities
- Structural elements: racism, ableism and intersections with other forms of marginalisation

ADVOCACY TAKES TWO BROAD FORMS IN THIS CONTEXT

- Individuals advocating for themselves in healthcare consultations (may also involve families, other professionals in those conversations)
- Groups, networks and organisations working to achieve change at broader levels
- Advocacy is about aiming to use your skills to effect *change* for a particular cause or group of people

THINGS TO THINK ABOUT IN GENERAL

- Not everyone who is pushing for change is aware that they are part of a broader cohort of people trying to effect this
- Awareness of others striving to create change can be helpful
- People can disagree on:
 - What changes are important, priorities, realistic
 - How to go about achieving this
- There are multiple different ways to achieve change

THE 3 AREAS THAT PEOPLE TEND TO FOCUS ON TO ACHIEVE CHANGE

- Personal empowerment – help individuals to build the power and capacity to effect change at an individual level to address issues they may face (e.g. individual healthcare consultations, training to navigate welfare benefits)
- Institutional change – Aim to bring about change at institutions (e.g. NHS) to bring about change for a larger group of people (e.g. by changing policies, campaigns)
- Building alternatives – Creating alternative institutions and cultures which explore different ways of doing and being (e.g. by setting up locally based organisations which may facilitate preventative care for people with sickle cell and educate a local community about this, housing cooperatives, community based sharing economies)



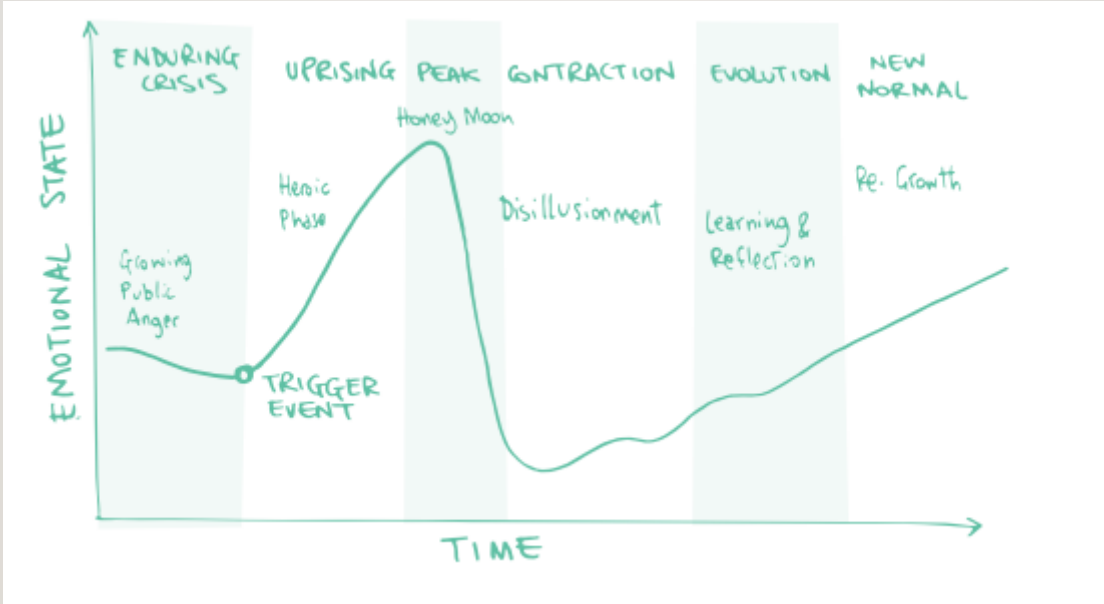
WHERE DO WE CURRENTLY SEE ACTION AROUND SICKLE CELL IN OUR CONTEXT

- Personal empowerment (e.g. navigating welfare system, health apts)
- Institutional change (e.g. APPG report, petition for free prescriptions)

What are the pros and cons of these approaches?



ACHIEVING CHANGE



WHAT DOES THIS MEAN?

- Change is not linear – there is no end point of utopia
- However, it is possible to ‘shift the needle’
- Noting the issues and putting ideas out there of how to address them meaningfully can be useful over time
- Trigger points can catalyse change – we tend to use the ideas that are *already present* as a guide for what changes need to happen (it is possible to create these)
- You may experience ups and downs in the energy that you and others around you have in trying to achieve change. This can be a good opportunity to pause, reflect and rest

COORDINATION

- If you have an idea of what others are doing, it is easier to not take on everything
 - Can also help with identifying gaps
- Groups of around 6 to focus on different things can be ideal
- Having different active and rest periods can allow for consistency (also allow for periods of illness, other demands and reduction in burnout risk)
- It can help to have common shared goals; and figure out what might be the right balance between the 'ideal' changes and 'realistic' changes for you/your group

YOU CAN'T CONTROL THE OUTCOME, BUT YOU CAN LEARN FROM WHAT YOU DO

- It is impossible to control the outcomes of what you do, or indeed the legacy of this work – it is important to connect with values and actions for that reason
- Reflection and learning periods can sustain a push for change, by allowing you to celebrate what has been achieved and learn from what has not worked out
- Support for yourselves and each other is also important (have covered this previously)

