

# TLC Showcase

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## Introduction to *It's time we got more radical about care*

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Lauren began writing her book at the start of the 2020 pandemic, a pandemic which has now brought millions more people unwillingly into the world of long-term illness and disability from sickness. The book is about how we live alongside illness and all its complexities. It reflects on what it's like to live in a sick body for 11+ years and the individual, structural and systemic ableism that disabled people have to face on a day to day basis. It speaks directly to those who are sick themselves, those that love them, those that long term sickness has never crossed their paths and those that want to learn more. The book explores a different topic each chapter and brings a mix of humour alongside the sometimes challenging topics and themes. Lauren writes with the main hope that those who are either new to long term illness or are long term veterans to illness, will feel an affinity and perhaps, feel less alone. This particular extract questions what self-care might look like for those who are ill or struggling in other ways. Lauren joined the TLC Chapter and Verse mentoring programme at the start of 2021 after receiving an Arts Council Funded place on their Free Reads Scheme. Over this time, she has worked closely with her brilliant and considerate editor Michelle Yaa Asantewa and attended an insightful TLC Industry Day. The mentorship has been invaluable to Lauren who has never written something so extensive before.

## Extract from *It's time we got more radical about care*

by Lauren Nathan-Lane

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Self-care when you're long term sick is incredibly important but sadly the idea of self-care seems to have been hijacked by the more toxic side of 'wellness'. In this chapter I'll discuss what self/care might look like if we move away from the expectation of always having to self/care alone and move more towards mutual aid and community care.

Somehow, over the years, self-care has been wrapped up in some shiny paper which has turned the idea of self-care into some prescribed, capitalist, green smoothie, hit the gym and spend a million pounds business. Which isn't just inaccessible to disabled people but also those on low or no incomes and many others. We shouldn't have to feel guilty about the fact we can't attain this level of self-care, just because we can't physically do it or afford it. When big corporations take on self-care, they target their campaigns to those who are able to spend money on spa treatments, those able to buy and prep daily smoothies, those able to attend Pilates and yoga retreats and gyms. But self-care is far more nuanced than a spinach smoothie and a yoga session. Without possibly realising it, these companies are being passively ablest.

Self-care for lots of disabled people is less likely to be as busy as this. Functioning day to day in a sick or disabled body is exhausting so of course we need to be compassionate to ourselves. But lots of us simply can't self/care a lot of the time. We can't always look after ourselves and our own needs which make self-care more complex. That doesn't mean though that it's not necessary for us because it very much is.

Care in all forms is important if you lead a difficult life and it's even more important if you dedicate any of your life to activism or campaigning. I and so many others use our very limited energy reserves to campaign for change for ourselves and others in challenging situations. It's essential we allow space to heal, rest and recoup before we can even start to try and change our small corner of the world. Yet we can also justifiably be angry that we are all desperately trying to self-care ourselves

out of huge systemic societal issues. There is no amount of self-care that will fix unending racism, homophobia, transphobia, sexism, ableism etc. We can't keep putting expectations on people who have experienced trauma from societal failings to simply self-care the pain away.

It goes without saying that self-care is different for everyone. For you, self-care might be remembering to ask for another prescription, making sure you bake a cake every weekend, making sure you go outside. But for me, self-care is;

- Anything that smells like lavender. Shower gel, pillow spray, soap.
- Limiting screen and social media time especially when I'm feeling bad about myself
- Telling the people around me when I am struggling
- Eating lots of fruit
- Trying to remember to refill my water bottle so I drink enough fluids
- Moisturising my face
- Buying pillows that make resting more comfy
- Being boundaried with my energy I use on different people (remembering who and what is deserving of my limited energy and who and what is not)
- Listening to guided sleep stories before bed
- Listening to funny podcasts
- And a big one- allowing people to care for me instead of always having to self/care.

There are many situations which can make caring for yourself alone practically impossible. Self-care is often sold to us as the be all and end all for mental health treatment. Especially in the UK where the mental health systems are in such a huge mess. People are told to just go away and do some self-care (by which they mean go have a cup of tea and a bubble bath) but what about those who are so physically or mentally unwell that they can't self/care? What about for those people for who self-care feels impossible? Are they not worthy just because they can't self-administer this care? Self-care takes self-labour and some people don't have the means to do that.

We need to start rethinking how we see self-care for anyone who the traditional means doesn't work for. For lots of people, the suggestion of taking some time out to have a bath and watch some Netflix alone in bed just isn't going to cut it or isn't within their abilities physically, mentally or financially. What everyone really needs, and especially those who are subject to long-term traumatic situations is other people to help them restore.

Essentially what I am talking about is mutual aid/community care. The popularity and awareness of mutual aid groups grew massively during the covid-19 pandemic but it has historically been a huge thing especially within marginalised groups and was originally used within many indigenous communities way before the actual coining of the term 'mutual aid' in the late 19th century. A prime example of mutual aid being used on mass was during the HIV/Aids epidemic. Mutual aid is a way for communities to survive whilst also acknowledging the powers that are causing the inequalities to exist in the first place.

Yet what we really need is constant and continual community and mutual aid support and not just when there is a crisis. It's already happening every day around the world, community care is already a big part of many non-western countries, I only have to travel home to Malaysia to see that.

The disability community are already so good at community care. I think there's something about people from similar identities and lived experiences as you, wanting to use what they have available to support each other. Mutual aid/community care exists in smaller forms already such as neighbourly support (sharing left overs) and local support (community hall clothes drives). But community care needs to go further than just marginalised people supporting one another. To be successful, people need to use what resources they have available to them to care for those unable to self-care and in turn, those people might use whatever means they have to care for someone else in way that's within their means. This is what a system moving away from capitalism and ableism might start to look like. Sometimes I think of the disabled community as a huge colony of ants, we use what we have in our power to try and make the world an easier or better place for each other on an individual and systemic levels. But what if it was more than just disabled people fighting this fight (or any other marginalised group for their own community)? What if we all

recognised where we might hold power in society and use that power to mutually support each other?

The way we think about care when it comes to disability needs a huge overhaul. Currently, society views those caring and those being cared for as a one way system but this just isn't true. Society currently views disabled people as adding no value to the world yet views their carer as a selfless individual who only gives but never receives. The issues with this are multi-pronged, firstly these views feed into the idea that disabled people are helpless, worthless and useless to society. It also portrays the carer as completely independent and the care as a one way system, but that person doing the caring is also reliant on others in some way and maybe even reliant on the disabled person themselves. Every single person is interdependent to other people in some way. For me, I need to sometimes be cared for physically by the people around me, I need help with cooking and cleaning and sometimes help with my mobility e.g. getting myself from bed to the bathroom. Lots of disabled people need round the clock physical care. But just because some of us need physical care support, it doesn't mean we don't also mutually support others. We might offer a listening ear to someone or be doing online activism. We might sit with the person giving the physical care and offer them some emotional care.

Independence is a myth. In some situations we are the care giver and in others we are the care receiver. They say no person is an island and it's true. We care for each other all the time even in small ways.

But imagine this; A community all living together, people from all backgrounds, with different needs and different skill sets. And we all utilise these skills to improve other people's lives without an expectation that that person will give back in the same way or at all. But knowing that that person is contributing back into the community in the way that keeps it moving and is appropriate for them. Some people are the physical carers (your gardeners, your cooks, your cleaners, your personal care support, your financial support aids). Some people are your emotional carers (your listeners, your activists, your shoulders to cry on, your child carers, your person you sit with in silence for company, your hand holders). Some people might be your creatives (your artists, writers, poets, painters, dancers, singers, knitters). We all work together and weave in and out roles to keep our community running but nobody judges how

much or little each gives and we all give in a way that is accessible to us. On some days, we may give a lot, and on other days, we may just rest and that's ok because we acknowledge that without rest, we can't keep the community moving forward.

I know this sounds totally idyllic and not possible but actually, concepts like this do already exist especially within more marginalised communities. If instead of the worlds focus being on money and punitive punishment for those struggling, and focused instead on care for each other, the planet and nature, imagine how different we might all feel.

For me, mutual aid and community care is the way we'll start to dismantle such an ablest world.

## About the Writer

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Lauren Nathan-Lane (She/Her), is a disabled writer and campaigner. She writes predominantly from her bed or sofa alongside her cat, Puzzle. When she is not writing her book or resting, she is campaigning for more disabled inclusivity within the fashion industry or working her part time job as a wellbeing officer for a youth mental health charity. She loves to read fiction thrillers and non-fiction about abolition, community and texts that can imagine the world in a different way.

