

CARING

MOVEMENTS

Chronic Illness

and Activism

TABLE OF CONTENTS:

INTRODUCTION: TOWARDS CARING MOVEMENTS _____	3
CONCEPTS OF “HEALTH” AND “ILLNESS” IN OUR CULTURE(S) _____	4
THE SYSTEM IS WORKING IN US _____	7
REFLECTIONS ON ATTITUDES AND RESPONSES TOWARDS ILLNESS IN OUR MOVEMENTS _____	8
WHAT COULD HELP? _____	12
LIVING WITH CHRONIC ILLNESS DISCUSSION WITH BETH, LINA AND AMANI FACILITATED BY LUCY _____	18
CONCLUSION _____	22

INTRODUCTION: TOWARDS CARING MOVEMENTS

This zine came together through experiences of living with chronic illness and giving care to someone who is dealing with chronic illness. We were both living on occupations, and generally involved with environmental movements. When the illness came, many of these activities became much more difficult or impossible to take part in. To some extent this was due to physical limitations brought by the illness, and to some extent by the lack of awareness for this within the movement. We began to notice the barriers to participation created by this lack of awareness, as well as by many tendencies carried over from mainstream society that seem to weaken our ability to care for one another and create a collective culture of caring. Often the focus was very much on action and concrete results and often care and time for those who couldn't be so active any more, whether due to chronic illness, trauma, burnout, or other issues, ended up not getting much priority.

That's certainly understandable in a world where it seems we have to fight as hard as we can for a livable planet, and where our resources for this struggle seem limited, but is it really how we are going to create strong, resilient movements that really make a difference?

We saw how structures within the movement tended to be built for healthy people, and how often even basic needs like quiet retreat spaces or basic day to day support with simple things like eating were not provided for. We saw that where this care did exist, it was often in the context of existing friendships, and that a collective response to chronic illness was in most cases lacking.

In this zine we want to explore these themes, looking at attitudes towards "health"&"illness" in mainstream society and in our movements, and some ideas about how to move towards more of a culture of caring.

Many of the frustrating experiences and lack of awareness and support within activist movements seem to be shared by lots of other people we met who are dealing with chronic illness. But of course, it's not all bad. It would be wrong to forget about the many acts of solidarity, the people who are aware of the need for more caring movements, and who try to realise this in the projects, gatherings and campaigns they are part of. And the friends who make sure to keep in touch, ask how we're doing, send nice punk post, who come to visit, who offer support in so many other ways.

This zine aims to bring attention to the experiences of people living with chronic sickness, and provoke reflection and discussion on how we respond to that in our movements

CONCEPTS OF “HEALTH” AND “ILLNESS” IN OUR CULTURE(S)

The dominant Western capitalist paradigm equates health with functionality: the medical system is thus aimed at diagnosing dysfunctions that remove us from the labour market and treatment of illness is aimed at restoring our ability to work. This is also true of and particularly alienating in mainstream treatment of psycho-emotional states.

Another aspect is the concept that “healthy” is the norm and “good”, as opposed to sick, which is seen as unusual and “bad”. This is reflected in the horrible use of the word “invalid” for people who are sick. The truth is that no such polarity exists; we are all constantly moving through different states of health and should be aware of that. Just because we are in a condition where we don't easily fit in to the capitalist system of work doesn't make us or our state of health “bad”.

In our culture, we often feel we have to hide illness, to feel ashamed, we are made to feel solely responsible. Or we feel that we have to strive for a norm that nobody fulfills, and that indeed isn't good for anyone. The very idea of “normality” can make us sick as we strive to live up to it.

There is a lack of understanding of the systemic aspect of illness, the factors of social injustice, environment, etc.

These tendencies are reflected in our day to day interactions. People push one another to work harder, judge each other for whether or not they appear to “contribute to society” and how. Often people are pushed to do more for their recovery when they are already doing their best, which can contribute to the feeling of not being good enough.

And there is often a terror and denial of illness, whether in ourselves or in others, a lack of acceptance that we don't all fit the same standard, that we can't always perform the way the system would like us to...

Instead of a focus on the whole picture of maintaining balance and living with our individual peculiarities and bodies, modern medicine is largely obsessed with a one-size-fits-all pathological model of health. Illness in this model is seen to be caused by “bad” bacteria, virus, cancers, or other destructive factors. The treatment focusses mainly on “fighting” these pathogens and/or, if unable to remove this cause, on alleviating the symptoms.

Although the science is beginning to move beyond this conception of health, in practise, in the minds of many doctors and lay people, and in the overall attitude of our culture, this model prevails. And although it's clear that modern medicine still doesn't have all the answers and doesn't completely understand health and illness, experiences and symptoms that cannot be explained through the current model are often labelled psychosomatic or misdiagnosed in some other way. Some illnesses also lack research and medicines because they would not bring in such a profit for the pharmaceutical companies. People may receive harmful treatments for many years, firmly assured by their doctors that they understand what is going on in their bodies while actually they have no clue. Others may not be believed, erroneously put on psychopharmaca, or denied access to the treatment, care & financial support that they need.

The medicines used are produced in laboratories in complex procedures which are impossible for us to replicate, and they often have a whole array of negative side effects, not to mention the heavy environmental and social costs and the suffering of laboratory animals during their production. This is all part of the process in which this culture is destroying our autonomy of health care. In how many lands has the vast majority lost even the knowledge of preparing a tea to remedy a cold? Our resulting dependence on the symptom-based pharmaceutical medicine is cheered on with glee by the huge corporations that are mass-producing these substances. Here is an ever-growing, lucrative market for an ever-expanding array of products. And so it goes on.

And so it comes that, for a cold, someone is prescribed antibiotics, which messes up their stomach. Next thing they are on pills for the stomach, which give them headaches so they get painkillers which mess up the stomach even more...and so it goes on. That's all too often the standard line. And the true causes are not addressed.

Of course, there's no denying that in many cases these medicines are life saving, sometimes indispensable. And of course, many doctors, nurses, researchers etc are working with good motivations. But unfortunately the emphasis on healthcare as just another market to be exploited means that once again profit is put before people.

This is sadly also often true of "alternative" healthcare products and medicines. Looking for answers outside of mainstream medicine can be confusing and we run the risk of being abused by companies and individuals that are only out for our money.

A large percentage of chronic illnesses are “invisible illnesses” which means that they cannot be easily noticed from the outside. People suffering from these illnesses, as well as having to endure the symptoms of their illness, also often suffer from a lack of belief from those around them. They may be (often based on first impressions) labelled as lazy, exaggerating, simulating, psychosomatic, and so on. This lack of belief, harmful enough in itself, can also manifest in a lack of the support they could really do with to help recover from their illness or live with it if recovery is not possible. This compounds the suffering caused through the illness and can leave people feeling alienated, misunderstood, and uncared for by the people around them and society as a whole. Resulting lack of financial support and the need to constantly fight for it is also a huge stress factor that adds to the difficulty of healing.

There is sadly often a lack of recognition and valuing of people’s efforts to get better from or to live with chronic illness. Although people who are ill may put in ten times as much effort as a “healthy” working person only to manage the basics, this effort is often not seen or not given the recognition it deserves. People can be left feeling like they are of less value because of not managing to fulfill expectations in capitalist society.

Modern medicine sees us as machines, broken down and come in for servicing. As well as this, health has become an industry and a market, just another field in which companies can make lucrative profits.

In our culture(s) there are many conditioned attitudes and behaviours towards illness, that can often make it harder to go through these experiences, that deny and pathologise vital parts of us, and that measure the worth of each person in their (apparent) contribution to the capitalist system. It’s worth looking critically to identify these patterns, in the cultures around us and in ourselves, to see how they affect us and others.

Looking at history, we can see that in the past communities and individuals often had a much closer connection to their own healthcare. We can also see events such as the witch hunts which were in part carried out to break this autonomy. Nowadays, we are largely cut off from this sense of having power over our own health. The power is written over to the Doctors, the “gods in white”, the ever more privatised professional healthcare services, and the pharmaceutical companies.

The ability of caring for each other has also been in large parts consumed into this profit-making structure. So we are often not used to setting up our own care structures, and assume that it will be taken care of by someone else, an assumption that makes us all that much more vulnerable.

THE SYSTEM IS WORKING IN US

Also in our movements and in activist spaces, we see many of these societal norms and concepts about illness (as well as about other things).

We are all brought up in this society, and there are many ways in which the system conditions our behaviours, identity and attitudes.

This conditioning is designed to disempower us, to alienate us from each other, from our bodies, from the world we are part of. It seeks to destroy our solidarity, mutual aid and support of one another, to assimilate us into the capitalist logic and break all possibility of resistance.

To be able to create new cultures, we need to do the inner work to dismantle this conditioning, otherwise we can end up just replicating the same destructive behaviours. We need to counteract this disempowerment through identifying and deconstructing these learned behaviours and attitudes.

Our activism cannot succeed unless we become aware of the system working in us. We must find and use the tools we need to break free and grow up anew.

It may be a long path but it is the path to real change in ourselves and in our world.

REFLECTIONS ON ATTITUDES AND RESPONSES TOWARDS ILLNESS IN OUR MOVEMENTS

Work Ethic. At least nominally, most of us would deny the capitalist logic that equates our status and worth with our job and productivity. However, in practice this work ethic has often been so deeply internalised that it continues in our movements. There can be a tendency to heroise people who do a lot, people who always go over their limits “for the cause”, and conversely to value people less when they appear to do less, or when they take more time for self-care.

As well as the simple admiration of “hard work”, different tasks and activities are also valued differently. This of course depends on the context and the experiences and attitudes of the people within that context, but for example people often receive more recognition and praise for direct action or building than for doing reproductive work like tidying up or doing the dishes. Emotional work often goes almost entirely unnoticed. Again, these tendencies are carried over from mainstream culture.

It is very important to take the time to reflect on what we value, as groups and as individuals, and why. When left unchallenged, these subconscious judgements can enforce the condition of only feeling good about ourselves and accepted by others when we “work hard”, thus impairing our ability to respect the limits and boundaries of ourselves and those around us. Because some tasks receive very little recognition, some people who take these tasks on more may end up feeling a low sense of worth despite actually doing a lot. A culture is created based on a hierarchy of who (appears to) work the hardest, and dependent on denying our needs.

Many people affected by chronic illness may be unable to keep up with such high levels of activity, may need to spend more of their time and energy on self-care, or may have difficulty with the forms of activity that are more highly valued in the movement. Lack of understanding for this within the group, together with unconscious enforcement of the “work ethic”, can lead people to feel forced to go over their limits or to feel guilty and alienated when they are not able to. This is clearly a dynamic that both excludes people with sickness from taking part in the movement and encourages burn-out and illness in others.

A large percentage of people with chronic illness have conditions that can't easily be seen, and this dynamic can affect them especially hard. Reflection on this "work ethic" is needed to come to an appreciation of different forms of activities and an acceptance that we all have our own rhythms and energy levels and are not machines.

Care as a "private" issue. Often we assume that everyone can function by themselves and take care of themselves. But when you are ill, you have to constantly make yourself vulnerable by asking for help, which can take a lot of energy and be very draining. How can we make it more normal that we help each other, so that it is easier for people to express their needs and ask for help when they need it?

When someone is in need of care, this tends to be seen as a "private" issue – to be taken care of by family or close friends. In many cases that ends up being a romantic partner. If the care work and/or treatment is beyond their capacity, usually the only option is to seek help from health professionals, for those who have the privilege to be able to do so.

So people end up entirely dependent on those caring for them to be able to attend events, gatherings, meetings and so on. That can certainly be quite an excluding factor. It's a shame, especially considering it often has to do with needs that could be quite easily provided for with more of a culture of caring and mutual aid. Mutual care for one another is a great strength which we need to reclaim from the system. Learning to look out for one another and not have to be ashamed of our needs can be very empowering.

Lack of care structures often forces people to depend on the system, and in many cases even to have to leave the movement. Others may be put off from joining in the first case, because they have to work to insure themselves in case of sickness.

Social Injustice and Chronic Illness: In terms of exactly who is being excluded from our movements when we fail to develop a culture of caring, it is also worth considering which social groups are more likely to:

- live in conditions that increase the chances of developing chronic sickness
- not have insurance/means of support when they get sick/have to work hard to secure that
- less likely to be able to depend on support from family or the system without working hard for it

Connected to social injustice are obviously also the questions of who is responsible for poor living conditions that lead to people getting sick, as well as for pollution, destruction, expropriation, war, climate change and other related factors for illness. It is clear that health and care in society are very much linked to social injustice and structures of oppression. That's one more reason to become aware and develop our own structures of caring and solidarity to increase both our autonomy from the system and the accessibility of our movements for people with different backgrounds, situations and needs.

These cultures of caring should at least attempt to make it possible for people to attend events when they don't have friends or family to accompany them to provide care. To collectivise the process of looking out for one another, to make it normal to ask for help or to offer it, and to recognise that we are all connected. To lift the burden of individual responsibility, guilt and shame that can be associated with illness and move towards solidarity in our actions and our structures.

Priorities within our Movements: How much priority do we put on care and looking out for one another? How much priority do we put on other activities?

In the long term, movements with stronger care structures and with more of a culture of caring will be more attractive and accessible to a far wider group of people, and more sustainable for the people within the movements.

Generally, thinking more long term will help our movements to be more resilient, and enable a more continued engagement without such loss of people and their experience and knowledge.

It's worth reflecting on what we prioritise and why, with an honest and critical regard, to be more effective in our activism as well as to create the world we want to see.

These are just some examples of tendencies that seem to occur in many situations. Everyone has their own experience and there are probably many factors not covered here, but this is a start.



Collage: mo

WHAT COULD HELP?

Here the focus is on how to improve accessibility within environmental and social justice movements for people dealing with chronic sickness.

THINGS WE CAN DO INDIVIDUALLY SO THAT PEOPLE FEEL MORE WELCOME AND ABLE TO TAKE PART IN OUR MOVEMENTS:

Ask what the person needs, and how you can work together in a supportive way, instead of trying to think of solutions without them. Trust them that they know best what is good for them.

Give people the feeling that they can ask for support when they need/want it without their projects being taken over.

Let them define and communicate their own boundaries rather than trying to tell them what they are allowed to/can do. Trust them to know their limits and don't take away their autonomy.

Show people respect for the efforts they have made in trying to recover/live with this illness. Often we focus too much on trying to suggest solutions, but its important to realise that this person probably knows much more than us on this subject, and to honour that. Only hearing advice of what they should be doing can be quite a pressure and gives the feeling that their own efforts are not valued or that others feel they are not doing enough to get better.

Don't just see the diagnosis or illness.

Keep an open communication so people can share and not have to feel ashamed or lonely. Take the initiative to make contact when you haven't heard from someone in a while, ask them sensitively how they are doing, and be open to hear what they might need.

Make sure they know that their friends are there for them even though they are not able to be so politically "active" at the moment. Show them that you are still interested in them, even though they are not currently able to take part in the activities that you used to share.

Show people that they are welcome in the group, even if they have been absent for a long period of time.

Let people know that they can be there, in whatever state of health they are in, that nobody expects them to go over their limits, and that it's OK for everyone that they just do what they can.

Make sure that people who are sick are not put under pressure to do things in order to be accepted, liked or valued. Develop more awareness of the hierarchy of "who does the most".

If someone is unable to travel much or get out of the house, it can be good to pay them a visit.

Help with practical things like visits to the doctor or sorting out benefits etc, and generally in dealing with stressful or exhausting situations.

Already just to be there as a friend, cooking together etc, is really helpful. You don't need to be an expert and you can do what you have energy for and what feels good for you.

Consider offering financial help if you can and if it seems like it would be helpful for the person. This is also another good reason for shared economies.

Don't take it too personally if the person gets grumpy with you. Be aware that it could be more to do with the illness than with you; instead of getting defensive and upset, stay calm and show empathy. Often the moment of anger will then pass. But be prepared to listen and consider whether your behaviour is disturbing or harming the person (some people with illness may be for example more sensitive to noise). Be aware that some illnesses are not so visible from the outside. Some people also mobilise a lot of energy when they are in the company of others, which is another reason it may be hard to see how sick they really are. It is very upsetting and tiring for people when they feel like others don't believe them or think they are exaggerating.

Take care of the people who take care of others. Be open for their needs such as a break from caring or someone to share their experience with. Make caring generally into more of a collective project and more visible in our movements.

Make the effort to identify and deconstruct your conditioning around illness.

Honour experience and presence of sick people, it is very valuable for everyone.

Don't just let people drop when they get sick!

THINGS WE CAN THINK ABOUT REGARDING OUR COLLECTIVE PRACTICES:

Some simple things to consider:

Broadening the range of activities within our movements for people with different needs and limitations.

Encouraging skillsharing that allows work to be shared, to avoid the dynamic of a few people doing very big tasks with a lot of responsibility, and allow people to take on workloads suitable for them.

Working against dynamics that heroise certain forms of activity but neglect others.

Other ideas

Creating restful, healing spaces for people who need them, whether sick for any reason or who need to get out of their day to day activism.

Developing our own healthcare structures for example with herbal gardens & pharmacies, solidarity doctors, skillshares, clinics...

Inclusivity within our movements, during events, gatherings etc.

If we want to value inclusivity, that also means to make our gathering places, our activities and our movements more accessible for people who have less energy. Probably the best way to find out how to do this is to ask people who are in that position.

However, when we look at the ways in which decisions are met and the possibilities people have for making their needs known, we find that this often takes place in meetings that themselves are not easily accessible when people have less energy. Often decisions are also formed in more informal settings like during social time so its also worth being aware of how inclusive those activities are.

So a good start would be in assessing:

- Are structures (like meetings) for identifying and addressing needs accessible for people who are ill? Can they make themselves heard? What stands in the way of them doing so?
- Are meetings facilitated to avoid tendencies like only the most dominant people or those who think quickly getting to speak?
- Is there space for the needs and concerns of sick people in meetings?

Some ideas for how to improve things in this regard:

Make sure to have time in meetings where we can share how we are, what we need in the moment to be able to take part in the meeting, and what we generally need to feel well on the action/camp/event/in the campaign. Depending on the situation, that could take place in the whole round, or in smaller groups or even pairs. Then organise how to meet those needs.

Generally having more ways of communicating within the movement or group will make it easier for people to take part. The same thing could apply to evaluating an event/action/etc on how to improve it for the next time. Be creative in using different ways to communicate and keep evaluating how inclusive they are.

MAKING MEETINGS/GATHERINGS MORE ACCESSIBLE FOR CHRONICALLY SICK PEOPLE

Some ideas from my own experience and from talking to people in similar situations, not based on thorough research.

Special needs

Before the event, mention that you would like to be inclusive and ask what peoples special needs are. Check in with yourselves if the organising team has the capacity to fulfill those or if it can be a task that can be done by participants (e.g. bring a person food).

Communicate clearly and realistically what is possible and what is not. It's good to

make an effort, but it doesn't make sense if you burn yourselves out in the process! Also it's better for a sick person not to come than to come and have a relapse of the sickness because the needs are not met.

It's also good to ask at the beginning of each session what people need to be able to participate, that makes it easier to articulate those needs.

Recordings/Live streams

Sometimes it's not possible to come to a gathering, consider making recordings or maybe even a livestream of events or if there are security concerns, take notes that can be shared. Like that people can still feel included in some way.

Be flexible

I can't predict how much energy I will have on a certain day, so it's nice to be open to people cancelling or plan sessions together with a few people, so that in case one person is too weak, others can take over their part. It's nice like that people can still facilitate sessions if they are well enough.

Meetings

Often decisions about the daily life on the camp takes place in meetings, which can often go on long and cover many different subjects, possibly excluding people with less energy.

It could be useful to have one meeting dedicated to the needs of people with illness, where they could share their needs and concerns so that others could represent them during decisions that would affect them but which they maybe don't have the energy to take part in. That could be daily, weekly, once during the event, or whatever is most suitable for the situation. This could also be a useful tool in more long term campaigns.

Health risks

Inform about health risks that are in the venue, like if it's outdoors are there ticks? Inform about tick transmitted illnesses. Old building, mold? Asbestos? ...For a weakened body, things like that can be particularly bad.

Hygiene

Chronically sick people often have weak immune systems or immune systems that are already dealing with a lot of other stuff so make sure to keep good hygiene standards, not only regular cleaning but also encourage people to wash their hands regularly, to have a few people wash the dishes for everyone after cleaning and disinfecting their hands, instead of everyone their own plate, maybe put tea tree oil in the water, have hand disinfectant around or at least vinegar...

Spaces to rest

It's good if there are quiet places to rest available as chronically sick people often have a higher need for rest.

Be aware about things like loud music and people's need for quiet time and sleep. When organising for example a camp, try and make quiet sleeping places available

that are as far as possible from any music. Take these needs seriously and be willing to party at a lower volume if that is the only solution. At the very least it's extremely important to be clear and honest about the level of noise there will be during invitations to camps and let people know if there will be loud music late at night on certain days. Then they can avoid the situation if they need to.

Are there comfy places to lie down in meetings/workshops where it's clear that the priority is for people who really need it? The lack of this is often enough to exclude some people from participating, and the lack of awareness that some people really need it makes it more difficult to ask when those spaces are occupied by people who would be able to sit up the whole time.

People might also be more sensitive to smell, so be open to accommodate for that if need be, for example have smoking areas far away from venues and also the doors. People with some health conditions may even be very badly affected by smoke and perfumes. Encourage mindfulness around that.

Special diets

It's good if the cooking team has capacity to accommodate for food allergies and/or if they are prepared to provide different options for common allergies (gluten...)

Mobility

When choosing the venue, check how easily reachable it is for people with less energy/walking issues, also how far is the toilet from the sleeping area, and the workshop places (for a person with little energy that can make a big difference).

Organising team

It can be good to invite a person who is sensitive to these issues to be part of or advise the organising team.

Small sections

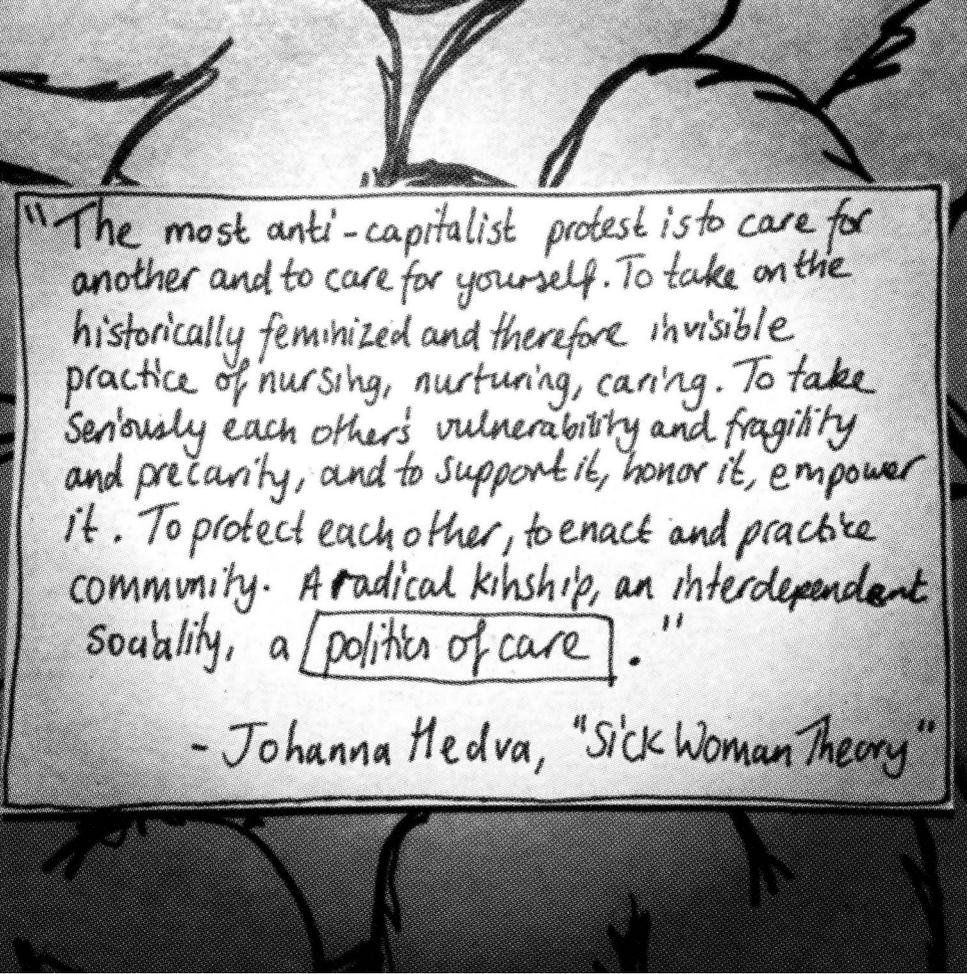
A lot of people with chronic sickness find it helpful if the sections are small, with frequent breaks, for me personally I can't participate a whole day, so it's great to spread long workshops over several days.

Money, money, money

Like other groups, chronically sick people often struggle with money. Medicine is expensive, plus it's harder if not impossible to make money, that's good to be aware of, so if you are able to support people, that is great.

Raise Awareness

Raise awareness during the event, like for example invite people to share their experiences so that people can develop understanding about those issues and also feel encouraged to share their own particularities. A lot of sicknesses are invisible and that often makes it hard to ask for help/receive help. A lot of people are willing to help if they know what to do. It's good if we think about ways in which we can support that process (with badges?, sessions where information is shared etc., buddy system etc.)



"The most anti-capitalist protest is to care for another and to care for yourself. To take on the historically feminized and therefore invisible practice of nursing, nurturing, caring. To take seriously each other's vulnerability and fragility and precarity, and to support it, honor it, empower it. To protect each other, to enact and practice community. A radical kinship, an interdependent sociality, a politics of care."

- Johanna Medva, "Sick Woman Theory"

LIVING WITH CHRONIC ILLNESS DISCUSSION WITH BETH, LINA AND AMANI FACILITATED BY LUCY

These notes were taken at a workshop during the Deep Water: Exploring Psycho-Emotional Experiences gathering at freiLand, Potsdam, in September 2017. Thanks to Julia for also taking notes, I have added anything that was missing from my notes out of those.

The discussion was structured in two parts, the first part based on several questions asked by the facilitator that were answered by the three people on the discussion panel, and the second part as an open discussion between everyone in the room.

PART 1 PANEL DISCUSSION

What impact does capitalism have on your psyche and your way of dealing with chronic illness?

Our sense of self-worth is often strongly linked to how much we can do.

We have a lot of self-judgement/inner critic about what society tells us we should be doing in life, and whether or not we live up to those internalised expectations. This makes illness so much worse.

Particularly sad that these kinds of patterns also continue in activist circles, not just in “mainstream” society.

There’s an assumption of society that everyone can function by themselves, take care of themselves. But when you are ill, even existing is so challenging, and you constantly have to make yourself vulnerable by asking for help. It’s relentless exposure. You see people’s expectations dissolve in their eyes when you say you can’t do a thing.

Being ill can make you less able to make commitments, lead to you being late for things etc. <You can’t predict how you are going to feel even the next day, let alone a month in advance.>

It hurts when others joke about me being unreliable, not understanding that I have to take care of myself.

The culture is very fast-paced, especially in cities. Its hard to accept that you can do less than other people.

When you’re sick, you have a lot more financial needs <medicines, better food, transport, doctors etc>, but at the same time it can be hard to get money, particularly when its an illness that’s hard to prove.

The attitude that you should push towards being able to work, to do more than you can and repeatedly go beyond your limits often makes the illness longer.

Capitalism gives us the image that we should all be shiny and healthy. This causes shame through the contrast with the ugly day-to-day reality of illness. <Why is my life like this?> The shame can lead you to individualising the situation instead of recognising the systemic aspect.

For example there can be shame coming from feelings that it must be your own fault that you're sick, for example that you aren't doing enough to get better.

The capitalist/cultural tendency to individualisation affects both "alternative" medicine and the "conventional" healthcare system.

In "alternative" medicine, you feel bad that there's such a wide array of ways to "help yourself", but you still aren't getting better.

"Conventional" medicine is so symptom-based that it doesn't really work for chronic illness. Doctors mostly don't want to hear what you know about your own health, <but rather think they know it all better anyway, "objective" measurements etc>.

There's a great lack of communication between specialists for different parts of the body, and often you have to make that communication yourself or it just doesn't happen. So often they miss really important stuff like that.

Different specialists all have their own theories about it.

The work of remembering and cataloguing all that is happening to you is so traumatic and the doctors have repeatedly treated me worse if I have tried to engage in my own treatment.

What are the psychoemotional impacts of chronic illness?

Being in pain, unable to do anything or even get out of bed, not having a good doctor; all these things can make you depressed.

Also as direct physical consequence of illness, the nerves may be affected, which can also lead to panic attacks, more need for space and quiet etc. Therefore afraid to leave the house.

When you are stuck in bed and a wave of anxiety comes, you are unable to release the "trauma energy" by doing physical stuff, like going for a run, and when you do push it anyway you can get overloaded & collapse. Stuck in that energy then which also takes its toll.

Instead of doing the things that are healthy for you, you haven't the energy to do self-care.

Despite loving life, feeling suicidal because of: being in agony, being unable to do enjoyable things, seeing your health going further and further downhill and feeling hopeless and helpless.

Some illnesses are more or less understood than others. When there is little dialogue in the society on your condition, you feel less confident because people don't

understand it or take it seriously. You can end up doubting yourself, wondering if you are making it all up, and constantly getting the feeling from others that they don't believe you. Its such an energy drain because you may feel that you have to convince them.

When you don't have a "proper" diagnosis you are always having to justify yourself, and put up with comments like ,just get up', ,do some sport', ,take a cold shower' (etc, etc).

I'm getting bored of hearing myself talk about my health issues, but at the same time so overwhelmed by my own pain that it's often hard to empathise with other people.

Psychoemotionally very hard not knowing when its going to end. Rejection of myself and my reality leads to shame.

Feeling of life not being fair.

Denial and not dealing with things.

Living with Chronic Illness within Radical Contexts

Led to me dropping out of the protest sites I was involved in.

- lack of awareness about people being sick
- priority on "the struggle" and doing actions
- not so much focus on taking care of those who needed it

I ended up falling back on my parents and the system because in the protest sites I couldn't meet my needs. Reliant on spaces where people don't understand me and my purposes in life.

Health and chronic illness can be overlooked and not prioritised.

How to make gatherings/spaces/movements open for people who are chronically ill?

For me, having the opportunity to do some computer work for herbalists without borders bristol that I could do from bed was good. It was essential for me to be able to be part of a project like that for my psycho-emotional health.

Being part of a shared house with friends, who also were helpful and understanding when for example I couldn't pay my rent, and so having a safe place to live, helped to work through burnout.

I still had to give up my projects, but I wasn't so isolated. I was only able to re-engage with projects when I was feeling better. But then I went back to the same patterns and did too much and got sick again!

Its hard and tiring to ask for help or for consideration of your special needs. This often leads to not going to some places and events.

She is sharing these experiences to hopefully educate people to offer help without being asked for it, because it's at the lowest moments that knowing what help you need and how to ask for it is the hardest.

PART 2 OPEN DISCUSSION

When supporting people - don't offer suggestions immediately. Ask if someone wants to talk about something and then an open ended question like how's it going? try to acknowledge how amazing it is that they know what they know and show appreciation for their journey.

We must create recovery space within movements.

A house for recovery, a place where people would live and could share experiences of burn out and illness.

What does it look like and feel like to be in a role of supporting someone? And what does your support look like?

It's essential that it's not just one person.

Supporting someone is an amazing way to learn a lot.

Offer to give someone who is supporting someone a day off.

It also doesn't have to be big support/big things.

Everyone could offer more awareness, creating a collectivised responsibility.

People have limited time so often they don't offer at all but just come and sit with me, work next to me - little bits really add up.

What can we do when we don't know what to do?

Learning what someone often needs over time so that you can be the communicator when they do not have the energy.

Asking the person what they need to stay well, if they are doing bad etc, working it out with them when they are not acutely in a crisis. Help them plan for flare ups. This is something we can initiate as it takes a lot of self worth to ask for help with these things.

Things that have been hard:

- tracking the illness
- food
- shelter
- finance
- having autonomy taken away

Pride comes in, not wanting to say

It's hard as a carer to acknowledge that you have emotions and feel things as you want to be strong.

Picking the right time with someone you are supporting and asking to talk about the perspective of supporting is an important thing to make space for.

Keep contact because people often cannot have energy to be nice.

CONCLUSION

This zine is a callout to make our movements more caring, to rethink our priorities, to widen our horizons, to reflect on our attitudes towards illness, to evaluate how we can make our groups and our actions more accessible and better adapted to the needs of different people.

It's also a thank you to all the people who are already implementing these things into their lives and their activism.

And generally to everyone who's heart is burning for an end to the violence and destruction that this modern culture perpetuates.

The path is long but we walk it step by step, and where we fall down or take a false way, we stand up again, we reorient ourselves, and acknowledging our failures find our way forward once more.

Of course this zine doesn't have all the answers or even all the questions. But hopefully it will be a motivation to reflect on these issues and to find out what they mean for us and those around us.

The best way we can figure these things out is to talk about them, give them awareness, recognising that diversity is the true "normality" also in relation to our state of health, breaking the illusory "otherness" of being "ill" or differing from the norm, and creating our movements compatible with the needs of everyone who takes part or would like to.

Opening spaces to explore reclaiming our health and our power of mutual aid collectively is also crucial. The Deep Water gathering in Potsdam Sept. 2017, where the discussion on chronic sickness that's written up in this zine took place, was one such space. The Radical Herbalism gatherings in England, Scotland and Germany and the networks that continue to grow roots beneath them are also fueling the momentum towards more solidarity and collective learning and action related to health and illness.

This is one more step to grow into stronger, more effective movements that can challenge the capitalist nightmare, and that recognise and honour the contributions, experiences and needs of all people.

Thanks for reading!

Any feedback, ideas for the next edition,
anything, you can email us at
radicalresilience@riseup.net

Check out
radicalresilience.noblogs.org
for updates on our film project around activist
burnout. Here will also be links and interviews
related to illness and activism.

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