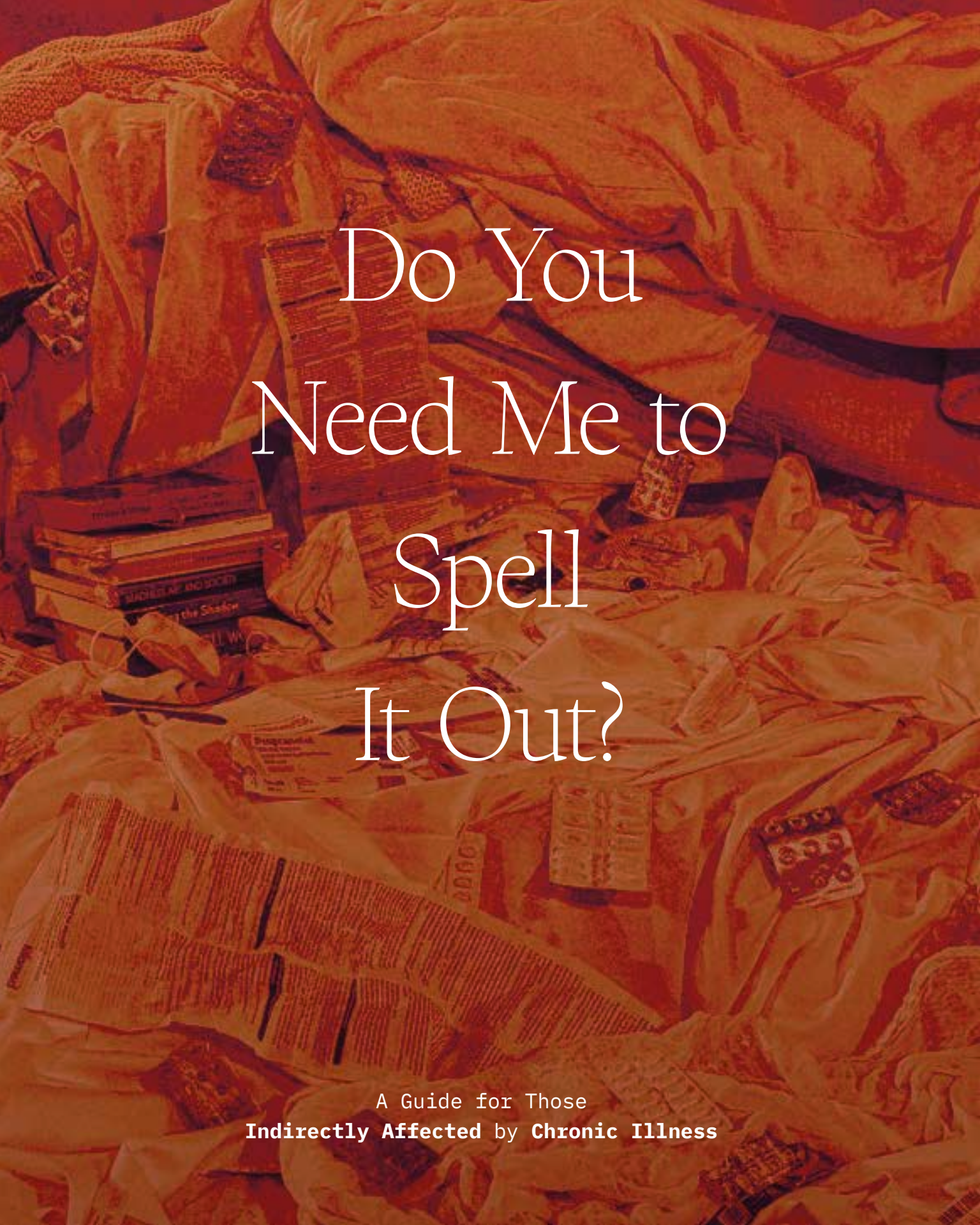
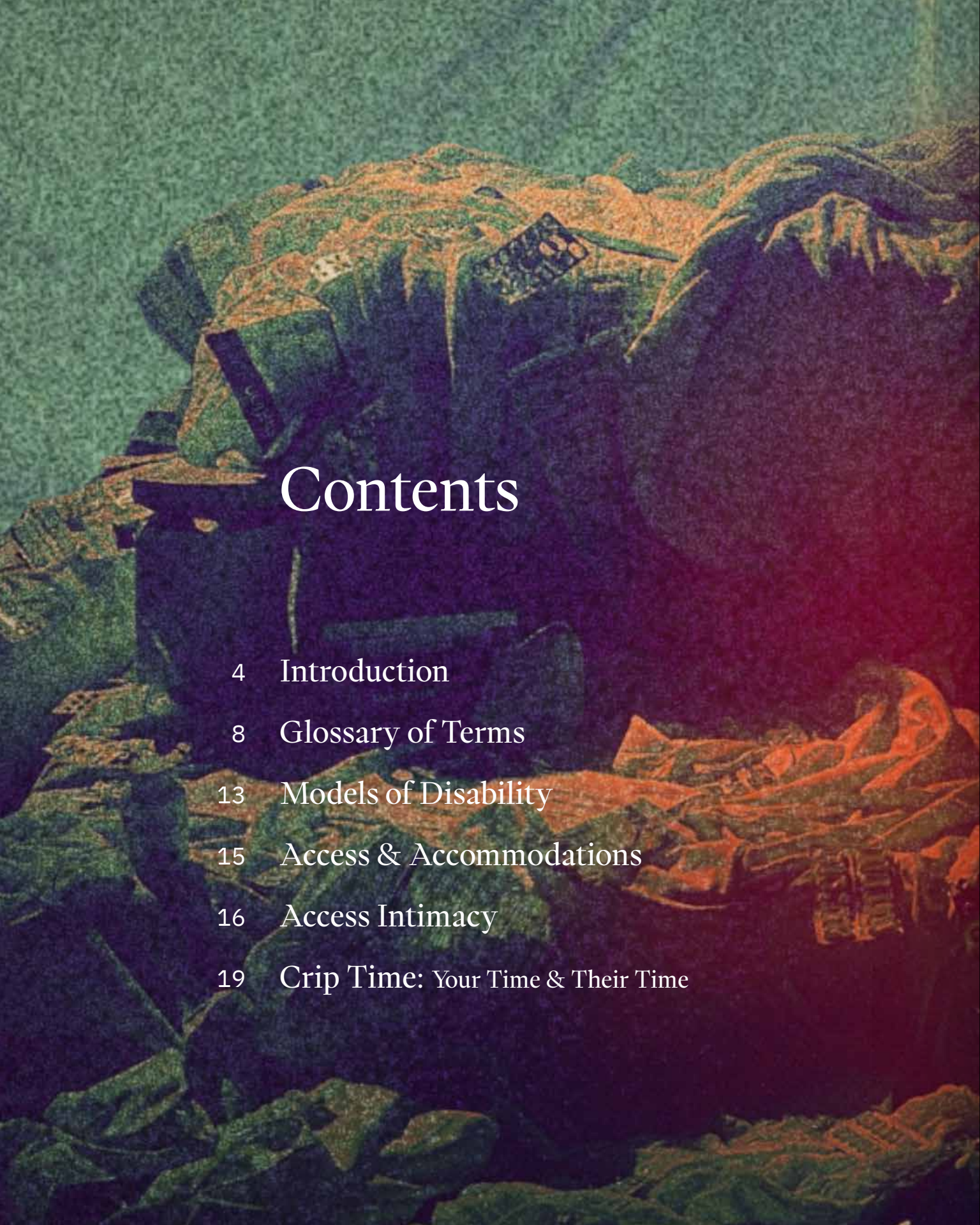


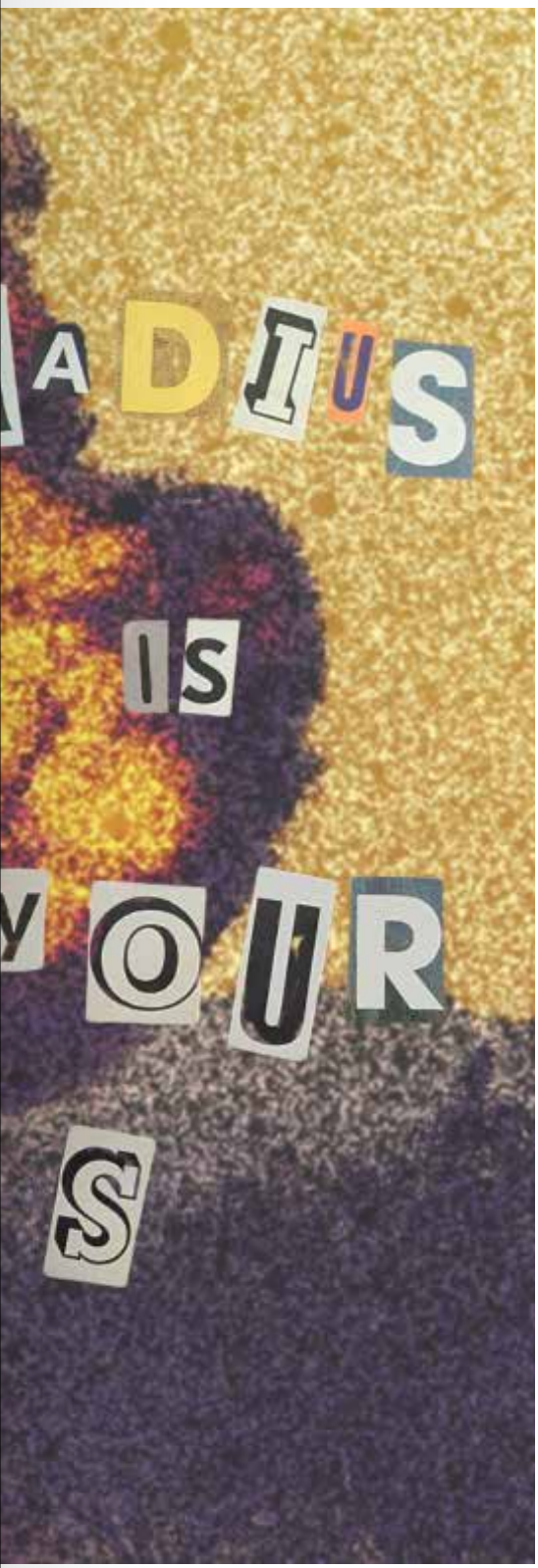
Do You Need Me to Spell It Out?

A Guide for Those
Indirectly Affected by **Chronic Illness**



Contents

Artwork by @thechronicoversharer_



Introduction

BY ANNA VAN MIERT

I've noticed a trend in my own life and the lives of others that live with chronic illness: **you get sick, you lose your friends.**

There are many reasons for this. Persistent sickness complicates every relationship. People recoil away from illness and disability because it feels awkward and difficult, and in many ways it is. Joanna Hedva speaks of 'the blast radius of disability'. For people who are not born disabled or sick there is a clear before and after; who you were before illness and who you are now. Hedva talks about how disability functions as a narrative pivot in people's life stories; 'a devouring cloud that won't stop eating everything'. **This cloud can devour every possible aspect of a person's life; their physical abilities, their financial independence, their hobbies, their diet, their mental health, and, more often than not, their relationships.**

I've found that in my own life all of the losses brought on by illness have been compounded by the breakdown of many of my friendships. I'm sure there are endless reasons for this. Maybe people don't want to say the wrong thing, maybe they feel awkward, maybe they are ignorant to the reality of what a life interrupted by illness looks like or of the impact their absence has. It's widely understood by the chronically ill and disabled community that people often recoil away from us because we remind them of their own vulnerabilities and mortality. As Sophie Strand says; **'to be a sick person is to know that you are always, simply by being alive and being unwell, someone else's rude awakening".**

I'm sure it's partly on us, too. The devouring cloud leaves us foggy and vulnerable and afraid, at least in the beginning. It's hard to accept and communicate your ever-changing needs and it can feel easier to isolate yourself than to continue to fight to keep up with a world that is so hostile towards you.

Navigating a life-changing illness or disability is hard work. You get sick. You spend an immense proportion of your energy battling to get NHS or privately funded treatments. **You learn to**

navigate a benefits system hellbent on undermining the complex needs of your new life. Your government openly ostracises those who do manage to claim support. You watch helplessly as parliament proposes drastic changes to life saving support like PIP while pushing for a new Assisted Dying Bill, simultaneously making it harder to live and easier to die. It's easy to feel like you're at odds with the world. We aren't always good at asking for help and our society hasn't exactly been set up to provide it.

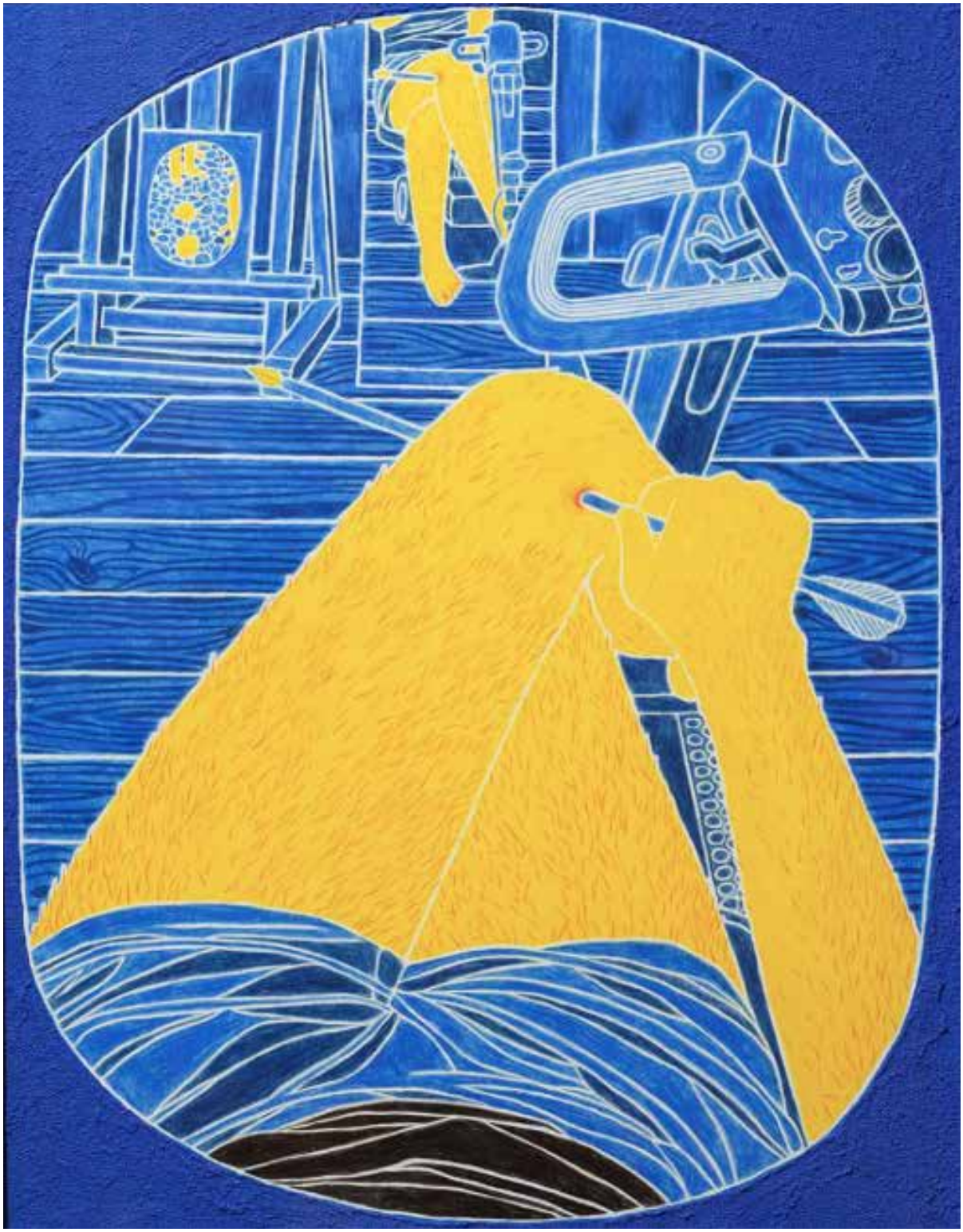
> "You've lost people—where did they go? The blast radius is chewing into your loved ones, your partners, friends, family. You start asking for help, trying to explain your new self and all of its embarrassing needs. I need help, I need someone to carry this for me, open this, move this, I need, need, need."
>
> **JOANNA HEDVA**
> HOW TO TELL WHEN WE WILL DIE, 2024

The breakdown of relationships and community experienced by chronically ill and disabled people can often feel just as unavoidable as the breakdown of our health. I think this needs to change. If you are an 'able bodied' person that wants to maintain a relationship with a sick / disabled person please remember: **You have the resources to fit into their world, they do not have the resources to fit into yours.** If that doesn't make sense to you right now, hopefully it will once you come to the end of this guide.

This is a guide to help educate those that care about people who are chronically ill but don't always know how to help.

‘Without Hope’/’Sin Esperanza’ (1945)
Frida Kahlo, 1907-1954

Thin Skin by @timothybair



Glossary of Terms

These are general terms and definitions used within the chronically ill community.

ABLEISM/DISABLISM:
Ableism is a set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities and often rests on the assumption that disabled people need to be 'fixed' in one form or the other.
Examples of ableism:

- Designing a building with no ramps or lifts for wheelchairs.
- Telling someone that they "don't look disabled" as a compliment.
- Choosing a non-disabled job candidate over a disabled one, because you think disability will make someone less productive.
- Ambulatory vs non ambulatory — Ambulatory means able to walk. In the context of illness and disability, these terms often refer to wheelchair users. An ambulatory wheelchair user is someone who uses a wheelchair but is still able to stand and/or walk. In the UK, about one third of wheelchair users are ambulatory.

CHRONIC FATIGUE VS CHRONIC FATIGUE SYNDROME AND ME
chronic fatigue is a symptom of many wide-ranging illnesses and conditions. Chronic Fatigue Syndrome, however, is a specific, usually life-long and debilitating condition, often discussed in disability spaces using the preferred names; Myalgic encephalomyelitis, ME or ME/CFS. Chronic fatigue, confusingly, is not the hallmark symptom of ME/CFS.

CHRONIC ILLNESS GRIEF
The ongoing grief that comes with: living in a body that has changed, reshaping personal and community identity, reduced capacity, and the imagined future.

CHRONIC/PERSISTENT PAIN
Any pain that lasts for more than 3 months (the pain is not necessarily happening 24/7, but it is frequent and disruptive). In contrast with acute pain.

ACUTE PAIN
Short-term pain that goes away within 3 months.

CRIP
From the word 'cripple', historically (and currently) used as a derogatory term for a disabled person, now reclaimed by some disabled and chronically ill people to describe themselves. Important in the academic field of disability studies, particularly in the development of crip theory.

CRIP THEORY
Crip theory is a specific element of the academic study of disability. It focuses on the lived experiences of disabled people, the intersections of oppression between disabled people, marginalised genders, racialised communities and queer communities. It explicitly acknowledges the social and institutional barriers to inclusion disabled people face.

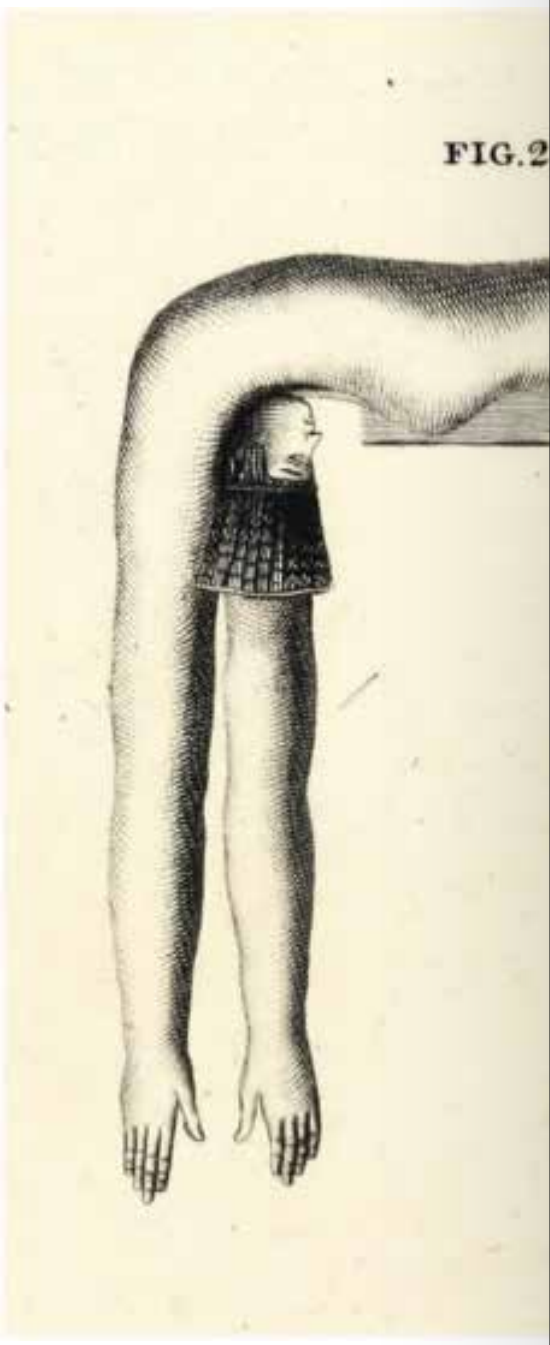
CRIP TIME
A concept describing how disabled people often experience and organise time differently due to access needs, fatigue, pain, or other symptoms. It recognises that everyday tasks may take longer or require careful pacing and planning, challenging linear, productivity-based expectations of time. Crip time is both a theory and a practice: an alternative way of navigating time and progress within an ableist world. (see the Crip Time section for more information)

DISABLED VS CHRONICALLY ILL
Not everyone who is chronically ill is disabled by their illness, and not everyone who is disabled has a chronic illness. Some people will be both chronically ill and disabled, but prefer one term over another.

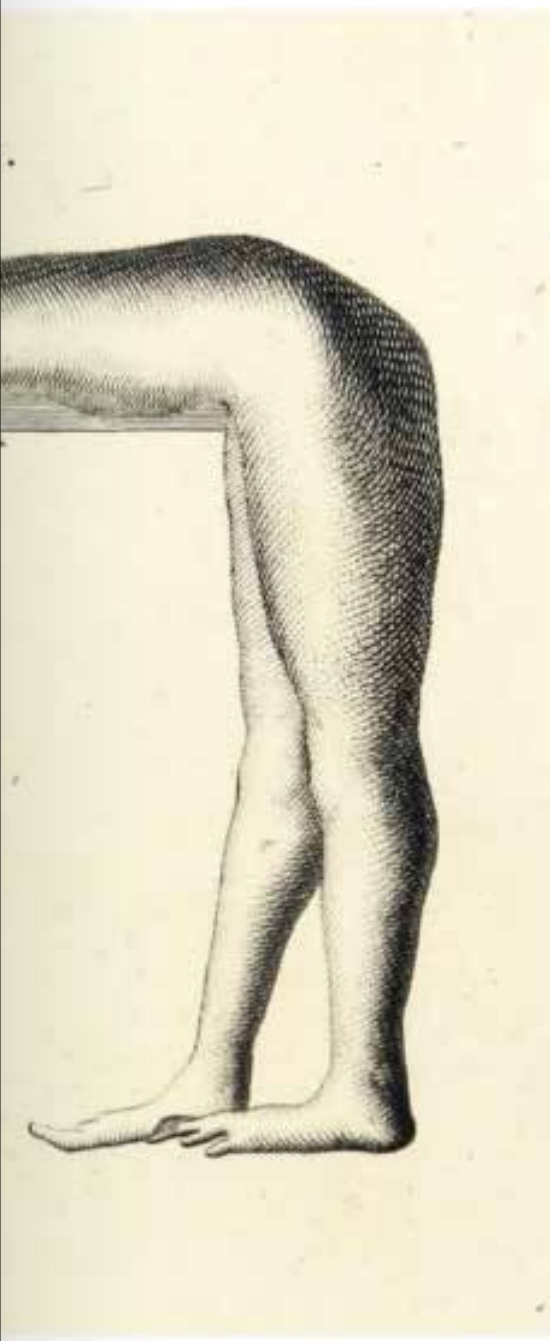
DYNAMIC DISABILITY
A dynamic disability refers to a condition or impairment that fluctuates in severity and impact over time. People with dynamic disabilities may be bedbound or unable to walk without aids on some days, but capable of moving around independently on other days.

ENERGY LIMITING ILLNESS / CONDITION (ELC)
Used to describe a wide range of conditions which negatively impact an individual's available energy, or which have fatigue as a common symptom. This is not a medical term but a term frequently used by those within the community themselves, and therefore it is up to individuals to self-identify (or not) with the term. Conditions commonly included in the ELC umbrella include Endometriosis, ME/CFS, Long Covid, Lupus, Multiple Sclerosis, cancers, thyroid disease and more.

FATIGUE
Fatigue is usually considered a state of extreme tiredness. Many people, disabled and non-disabled, will experience fatigue throughout their lives. For disabled people, fatigue may be a constant state they live in, which is not relieved by either rest



Artwork by Charles Sigisbert (1799)



or sleep. Fatigue can make thinking feel like swimming through honey, and moving feel like you are being crushed with each step.

FLARE UP
An increase in pain, fatigue, or other symptoms of a chronic condition. Flare-ups are usually temporary (though may take hours, days, or weeks to ease back to a 'baseline') and often occur after over-exertion, or due to medication changes, treatment, stress, or other factors, though they can also happen for no apparent reason.

GLIMMER (ALTERNATIVE TO TOXIC POSITIVITY)
A glimmer is often considered the opposite of a trigger. It is a small, often seemingly innocuous moment or noticing which brings joy and safety. Recognising a glimmer is a mindful act. Often-described glimmers are sunlight through the blinds, the first sip of a hot cup of tea, wearing your favourite jumper. The practice of recognising glimmers is often said to support the brain to notice good things more easily, without the dismissal of toxic positivity.

INVISIBLE/HIDDEN DISABILITY
Term used for disabilities or illnesses that usually cannot be seen, such as chronic pain or fatigue, in contrast to more visible disabilities such as limb difference.

MEDICAL GASLIGHTING
Medical Gaslighting — When a doctor or other healthcare professional ignores/dismisses/invalidates a patient's concerns, symptoms, or conditions. This can look like: blaming symptoms on anxiety or stress, or your weight/age/gender; rushing appointments; refusing tests; assuming a 'normal' test result means nothing is wrong. Disproportionately affects women and minority groups.

POST EXERTIONAL MALAISE (PEM)
PEM is the hallmark symptom of ME/CFS, and also occurs in Long Covid. It is unique to these conditions. It is the delayed exacerbation of symptoms following mental, physical, social or emotional exertion, disproportionate to the level of exertion. It is also known as Post Exertional Symptom Exacerbation (PESE) and less often Post-Exertional NeuroImmune Exhaustion (PENE). It is often described as a feeling of being poisoned and can lead to long-term or permanent loss of capacity.

PRIMARY CHRONIC PAIN
Pain that has no clear underlying condition or appears to be out of proportion to any observable injury or disease, e.g. Fibromyalgia.

SECONDARY CHRONIC PAIN
Pain that is a symptom of an underlying condition, e.g. the result of an injury, surgery, a disease, etc.

SPOON THEORY
A concept to describe the experience of having an energy-limiting condition, coined by Christine Miserandino in 2003, using spoons as a metaphor for how much energy an individual has. A chronically ill person may only have 3 'spoons' of energy to use per day, vs an able-bodied person who may have nearly unlimited 'spoons'. Everyday actions such as taking a shower might cost 1 'spoon', which leaves the chronically ill person with only 2 spoons remaining for the day, vs the able-bodied person's still nearly unlimited spoons.

SPOONIE
From spoon theory, a term used by some disabled and chronically ill people to describe themselves, and to form communities with other 'spoonies'.

TITRATION
A process of pacing, where overwhelming memories or experiences are accessed in small, manageable doses to prevent nervous system overload.

TITRATION (MEDICAL)
The process of slowly adjusting dosage when starting a medication, to find the 'sweet spot' of effective treatment of symptoms while minimising side effects. Also used when coming off a drug, to reduce unpleasant or prevent dangerous effects of stopping 'cold turkey'. Applicable to drugs such as sedatives and anti-depressants (including those used to treat chronic pain).

TOXIC POSITIVITY
An excessively positive response to a given situation, often used by non-disabled people to make themselves feel better about their disabled peers' complicated emotions or difficult circumstances. Usually, it is combined with dismissal and the inability to hold space for negative feelings or experiences. An example might be a chronically ill person saying, "I''ve been given this diagnosis and it's really upsetting" and their friend responding "At least you have a diagnosis now!"; or, you telling your flatmate you've had a bad day and them just replying "tomorrow will be better!".

Models of Disability

There are many models used to conceptualise disability. Most disability centred organisations operate using the social model of disability—this resource also uses the social model.

THE SOCIAL MODEL OF DISABILITY

The social model of disability explains disability as something created by society. People are disabled by physical, social, and attitudinal barriers, not their impairment(s). E.g., inaccessible buildings or assumptions about what disabled people can or cannot do. In this model, someone who is unable to stand is not disabled by their lack of ability, they are disabled by their job / housing / leisure activities not having proper wheelchair access.

The model makes an important distinction between **impairment** and **disability.** An impairment refers to a physical, sensory, or mental difference a person has, while disability is the exclusion or restriction someone experiences when society does not accommodate that impairment. From this perspective, disability is a form of social oppression, caused by political, economic, and cultural systems that fail to include disabled people.

The social model of disability is generally preferred by disabled people, and is the model used within this guide. However, some disabled people criticise it for minimising the inherent disablement some symptoms cause.

THE MEDICAL MODEL OF DISABILITY

The medical model of disability views disability as a problem within the individual, caused by a physical or mental impairment that should be treated, fixed, or cured. It focuses on what is “wrong” with the person rather than on the barriers they face, often leading to low expectations and reduced independence, choice, and control. This model assumes impairments are the reason disabled people cannot fully participate in society and has strongly influenced laws, services, and attitudes, often promoting harmful ideas of normality and reinforcing discrimination.

The aim of this model is to help disabled people live more “normal” lives. Stereotypical language based on a Medical Model of Disability reinforces a negative view of disabled people while

at the same time disguising the social and economic basis of the barriers disabled people face. It is often understood to be eugenic in nature, by assuming (wrongfully) that physical/chemical/mental differences are “abnormal” and should be normalised. Rather, many disabled people, and scholars, acknowledge that differences are natural and unavoidable, and that the goal of eliminating them completely seems like a concerning eugenic move to eradicate disabled people.

Artwork by @kirstybunce.art

Access & Accommodations

ACCESS AND ACCESSIBILITY

Access needs are conditions that you need to be able to engage within an event, activity or society generally.

Everyone has access needs, including non-disabled people. For example, if you are a sighted person, you likely need lights on to read. As the social model explains, the reason you don't think about these things as access needs is because you can expect that in most public places you go, these needs will be accommodated. E.g. There are street lights so that you can read road signs at night.

An example of an access need that is not always met would be lifts for people with mobility issues or sign language interpretation for d/Deaf people. Many disabled people have access needs that are very individual to them, which can be extra challenging to meet - such as having a place to lie down to rest, quiet/dark spaces for sensory needs, or reduced/flexible working hours. Access needs are not just preferences, they are things that, if not met, will impact someone's ability to do something.

ACTIVITY

Think about your access needs, what things are important for you to be able to do your day to day activities?

It's impossible to make a hangout universally accessible because access needs can sometimes conflict. This can be difficult to negotiate, the only way to do so is to talk about it with the people involved and ask what they are able and willing to accommodate to some degree, even if it's not an ideal situation. The most important thing is to show people that their needs are held in mind—this is one of the essentials for being a good friend to a disabled person.

Ask your disabled friends about their access needs. Consider their access needs when you are making plans so they don't have to repeatedly explain the basics to you. Check in with them to see if they need anything else - many people's access needs fluctuate depending on the day or even the hour.

It is important to consider social context and intersectionality when making decisions about access. If you are someone who doesn't often have to worry about whether something will be accessible to you, consider prioritising the needs of those who do.

Access Intimacy

Access Intimacy refers to the feeling of being seen and understood in the context of access needs. It's a term first coined by activist Mia Mingus on a blogpost that went viral back in 2010. She describes Access Intimacy as 'that elusive, hard to describe feeling when someone else "gets" your access needs. The kind of eerie comfort that your disabled self feels with someone on a purely access level. [...] It could also be the way your body relaxes and opens up with someone when all your access needs are being met.'

> "that elusive, hard to describe feeling when someone else "gets" your access needs. The kind of eerie comfort that your disabled self feels with someone on a purely access level. [...] It could also be the way your body relaxes and opens up with someone when all your access needs are being met."
>
> MIA MINGUS

Experiencing Access Intimacy is such a relief in a world where we are constantly having to justify our behaviours and boundaries. Disabled people often feel access intimacy with other disabled people as they share a common understanding of access needs. Mia Mingus describes the Access Intimacy between disabled people as an automatic ability to hold the weight, emotion, logistics, isolation, trauma and anxiety of access. But Access Intimacy does not only exist amongst disabled peers, it can exist with anyone. We may never experience Access Intimacy with some family members or friends but experience it with strangers on the bus who offer us a seat or an acquaintance who offers us a cup of tea or a soft drink when they notice we are the only person not drinking alcohol at a social event.

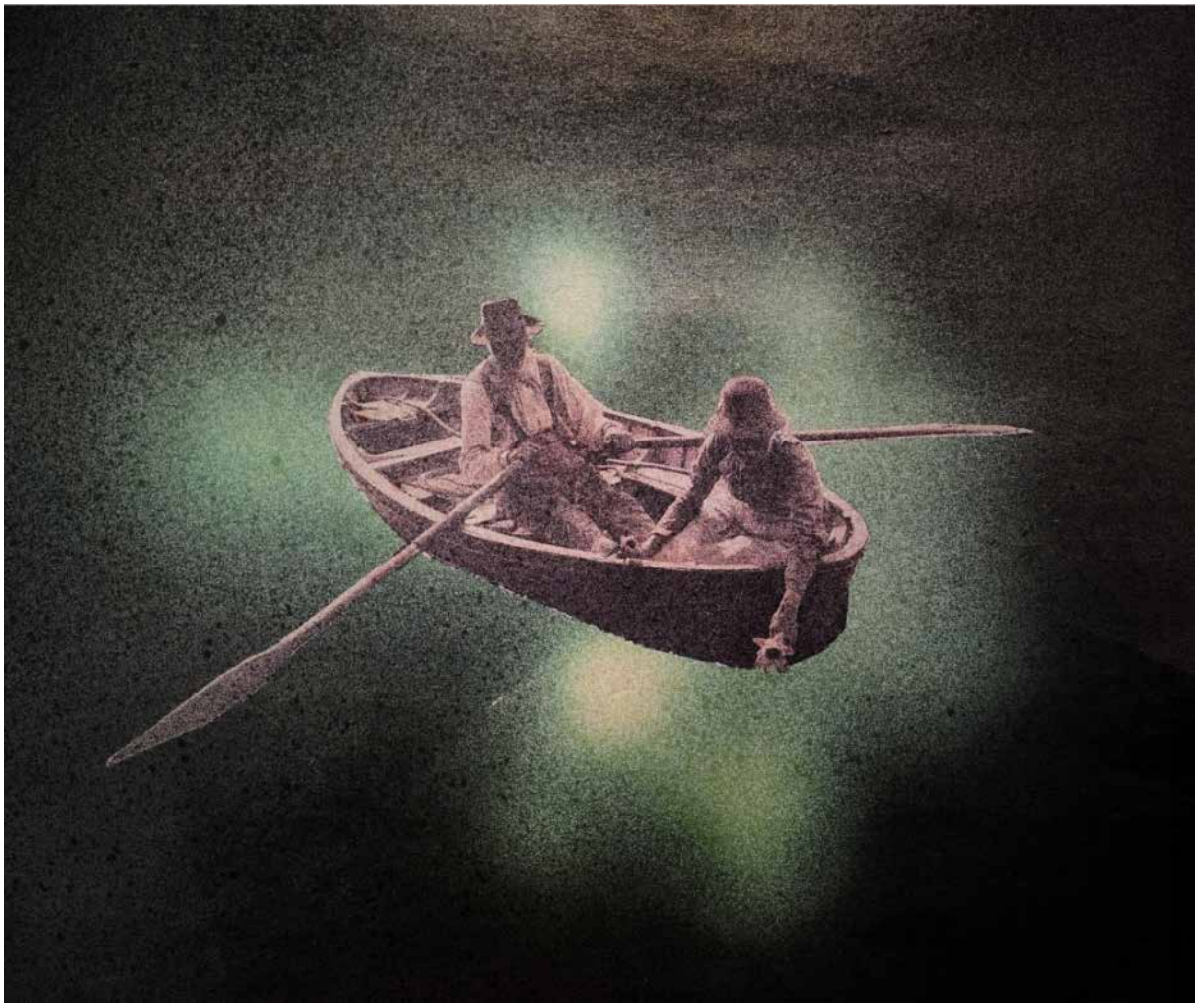
At its core, it's the sense that the people around you are genuinely happy and glad to hold your needs in mind, rather than making you feel like a nuisance or a burden. Sometimes it's easiest to understand the concept by looking at what it isn't: for example, someone begrudgingly doing your washing up while you're in a flare and making a passive aggressive comment about it is the exact opposite of access intimacy.

You don't need to be a disability scholar or a saint to create Access Intimacy for your disabled friends. As Mia Mingus says 'sometimes Access Intimacy doesn't even mean that everything is 100% accessible. Sometimes it looks like both of you trying to create access as hard as you can with no avail in an ableist world.' Access Intimacy takes many forms. It can look like anticipating that your friend may need a rest break during a hangout, choosing meeting places with comfortable seating and good back support, offering to carry their bag on a walk, or speaking up if someone says something offensive or ableist at a social event.

> "Without [access intimacy] relationships exist under a glass ceiling or split by thick frosted windows, with huge pieces of myself never being able to be reached. Without it, there is survival, but rarely true, whole connection."
>
> **MIA MINGUS**

Artwork by @KYRIANNA

Artwork by @miel_celeste



Crip Time: Your Time and Their Time

BY MIEL CELESTE

Time isn't something you too think much about when you're well. At least not how it permeates and shapes your reality. Time sits neatly next to your life, like a porous tape measure used to establish the parameters of human existence. Time is an invention, created over 4000 years ago somewhere in Ancient Egypt, along with sundials and pocket watches - and like any invention, its innate design can be inaccessible. We can view time as socially constructed, we might even view it as scientifically constructed.

When you're disabled and/or chronically ill, times' seemingly linear line distorts and glitches. Time rolls back and forth like the tide. Milestones are put on hold, or appear more like temporary medals, than monuments fixed in time. In Six Ways Of Looking at Crip Time', Ellen Samuels describes the notion of Crip time as a form of "time travel". Samuels goes on to state that, "Disability and illness have the power to extract us from linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings". So, whilst you may picture your time to only ever march forward, Crip time marches in circles, like rings held in a tree stump. Crip time expands whilst retracing old steps. Sickness can make it feel like you are tied to one origin point, like the arm of a compass, you can only stray so far from the epicentre.

We can start to build a picture of how our differing relationships with time construct different lived realities.Your time inhabits an energy of action and movement, like a yo-yo with a never-ending string to hurtle upwards. Disability stagnates, it repeats, it digs its feet in the dirt with boots made of iron. So, whilst existing in seemingly separate plains of existence, how might we bridge this gap? First, we must consider the differences between our timelines, how one body has to work harder to carve out this shared time. It is a constant process of budgeting, an incessant cost benefit analysis of bodily resources.

> "Disability and illness have the power to extract us from linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings".
>
> **ELLEN SAMUELS**
> SIX WAYS OF LOOKING AT CRIP TIME

Let's take a seemingly simple coffee date one afternoon as an example. Before this meeting even occurs, disabled people must gather enough spoons to facilitate the parameters of the plans. Perhaps they've had to choose a week that they didn't have any medical appointments, or even delay those appointments against their better judgement. Maybe they had to skip showers, meals, leisure activities.

They might have had to schedule a day, two, three, more, of total rest before and after this little coffee date. Lying in complete darkness. Silence. These are the negotiations Crip time requires.

Now, let's say you cancel. For whatever reason. However near or far from the intended date and time. For you, it may only be that afternoon that is affected. For them, it dismantles those days, the hours of preparation now redundant. That time does not come free. The rearranging of Crip time does not come without consequence.

"But, it's just a coffee date, and these things happen" I hear you cry! For you, these few hours in a corner of a cafe may not be the pinnacle of your plans. For your disabled friend, this could be the one social activity they were able to budget for the month.

Okay, so maybe you don't cancel, but attempt to change the exact time, location, or activity. Maybe, you want to go bowling in the evening instead, and you've invited a few other people along. The initial equation is completely thrown off. A new equation must furiously be calculated and executed in order for the disabled body to distort themselves to fit this new plan. The new parameters you have proposed; a physical activity, multiple people, a new location- drastically alter the energy your disabled friend has to gather.

Suddenly a whole herd of new variables flood in. Is the location accessible? Will it be too loud? Do I have the energy saved to do this? Do I know these people? If I don't, will they be accommodating of my limitations? Do I have enough recovery time planned for this activity? If the answer to too many, or any, of these questions is no, your disabled friend is the one who has to miss out. Their world shrinks, whilst yours keeps turning. Their time stops, yours keeps ticking.

"But, my disabled friend cancels all the time", whilst this may be true, and anyone cancelling at the last minute is inconvenient, for you this cancellation will only disrupt your afternoon. It puts a question mark between the allotted activities that line up nicely in your linear calendar.

> "we rage silently—or not so silently—at the calm straightforwardness of those who live in the sheltered space of normative time"
>
> **ELLEN SAMUELS**
> SIX WAYS OF LOOKING AT CRIP TIME

Let's imagine your chronically ill friend doesn't cancel, even if their body is screaming for them too. They push through and see you, they spend maybe two hours, at a push, trying to decipher your life updates between the radio static of fatigue. Your friend bridges the gap between timelines, however, this extension of time does not come without repercussions. For time to have been shared with you, your friend will lose time.

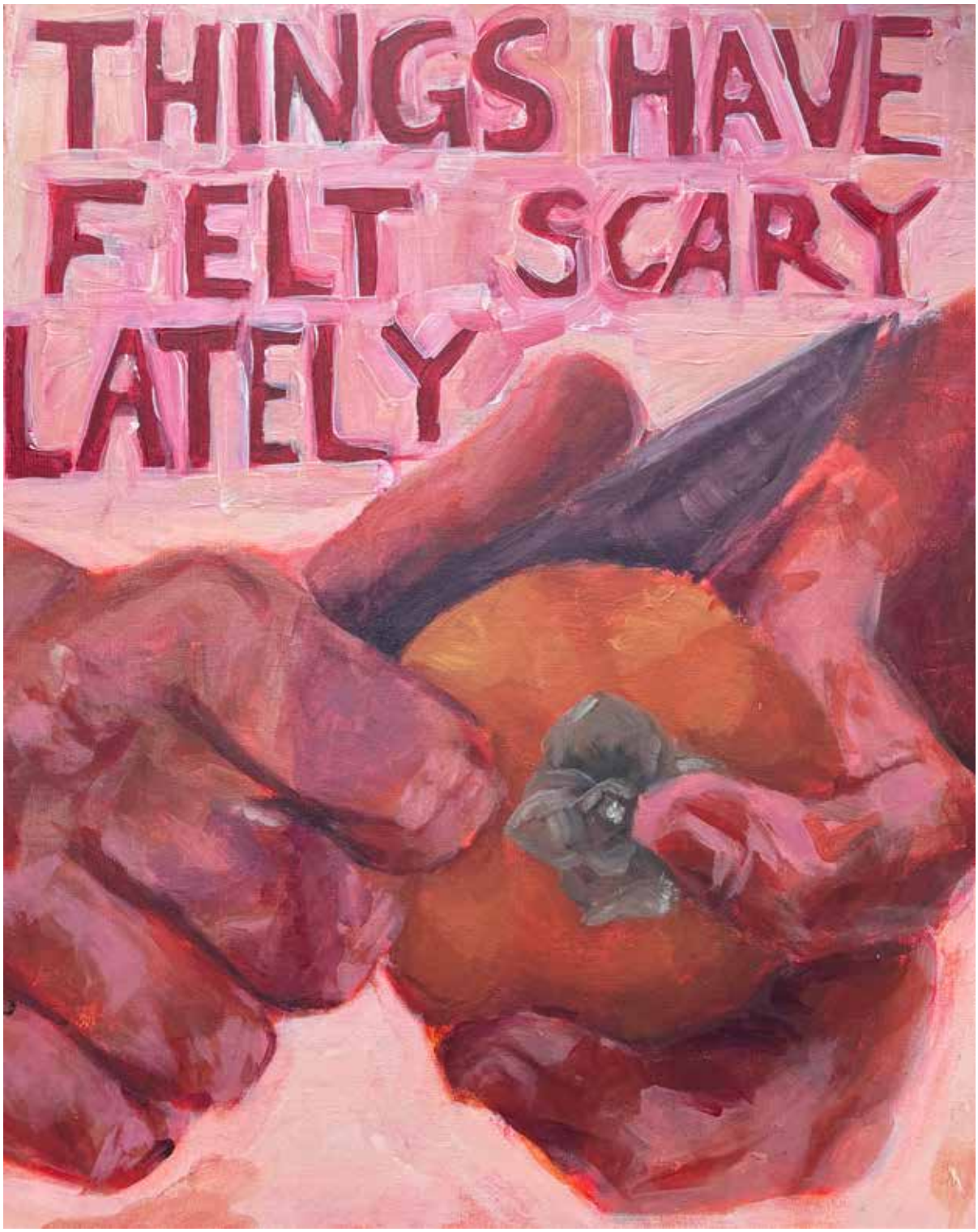
Crip time can freeze the world around you. When a disabled person overspends their energy, catapulting themselves into a flare, they can lose their baseline capacity for months. It can even result in weeks of total rest. Every disabled body has its own unique limits, and yet we all can damage ourselves in the pursuit of joy.

If your friend cancels, it is not because they don't care enough to make the effort, often for disabled folk it is heartbreaking to have to cancel in the first place. The disappointment and guilt of cancelling is only exacerbated by the initial catalyst of sickness itself. In this way we can see how the fallout always hits the disabled body harder. The impact ripples outwards, interfering with the puppet strings of the future. Whilst your time is yet to be written, Crip time unfurls before each decision, like a fortune teller reading tarot cards.

Your time is malleable and durable like clay, Crip time is fragile and temperamental like porcelain; it takes a gentle touch and great patience. However, in the cultivation of the ceramic nature of shared time, something beautiful can be forged.

'A Swooning Lady', late 19th century
The Metropolitan Museum of Art, New York

Artwork by @sunthruthewindow



Chronic Illness Grief

BY MADELEINE ALICE

GRIEF REQUIRES LOSS

Grief doesn't require death. Living with chronic illness means living with ongoing loss as capacity shifts, roles change, plans dissolve, and parts of life fall away. This is often called disenfranchised grief. As Kenneth Doka defines it,"grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, socially validated, or publicly mourned." There's no funeral, life appears to continue and yet is forever changed.

Relating to grief in a conscious way involves language, community, compassion, art, titration and marking thresholds/moments of loss. These skills provide containment & support in moving through the natural process of metabolising painful experiences. You can become a vital element of the person developing a healthier relationship with their loss. When isolation occurs (frequently experienced by those with chronic illness), further suffering is created through grief becoming stagnant and unprocessed. The role of community and considerate support systems are vital in navigating the complex terrain of the emotional landscape for those living with chronic illness.

CYCLICAL, NOT LINEAR

Chronic illness grief isn't about "moving on." It's about integrating an ever-changing ongoing reality. While resilience and positivity are often encouraged, pressure to move on can become a form of bypassing. It attempts to skip the depth of what is actually being processed. Many people are familiar with the five stages of grief described by Elisabeth Kübler-Ross while working with people facing terminal diagnoses: denial, anger, bargaining, depression, acceptance. These were observations, not instructions. Chronic illness grief differs in a crucial way — living within a multitude of endings rather than preparing for death.

Grief moves in a spiral, revisiting familiar terrain with new information and requiring repetition, space, and rest. There will be rage, numbness, resentment, and rawness. They're a human response to a life changed. There's no timeline. This will not be "gotten over." This is the ongoing work of redefining a life. Important to be acknowledged as recalibration rather than to be perceived as regression.

THE SCALE OF LOSS

When chronically ill, common themes of loss are:

- The body they once had
- The future they imagined
- Their independence
- Financial stability
- Career or creative identity
- Their role in family or community
- Their sense of belonging

It may also include rehoming a pet, leaving an inaccessible home, stepping back from activism or community work, losing daily rituals, or family estrangement. Alongside external change is an internal reckoning. Chronic illness confronts someone with limitation, alongside often bringing them into closer contact with

mortality. Even when not terminal, serious illness fractures the illusion of invulnerability. The body becomes unpredictable. This can destabilise a sense of safety, intensify existential questioning, and create hyper-vigilance around symptoms. It can also clarify values and sharpen awareness of what matters.

Recognising chronic illness grief often sounds like, “I miss who I used to be.” “I’m tired of cancelling.” “I don’t recognise my body anymore.” “Everything feels smaller.” It can sound like, “I should be handling this better,” or “Why can’t I just push through?” It may appear as irritability after a flare, silence in conversations about the future, or a quiet, repeated “this isn’t what I planned.” These are not signs of weakness or inability to adapt, they are signals of loss. Naming them as grief rather than encouraging positive reframing supports the individual in recognising and accessing self compassion whilst tending to what’s present.

Grief is deeply personal. What devastates one person may feel tolerable or even relieving to another. Centre the individual experience. Ask thoughtful questions. Follow their lead. Supportive and validating words may be “This is a lot.” “I can see how much has shifted.” “It makes sense that this hurts.” Follow their pacing, some days they will want to speak about loss, other days they will need space from it.

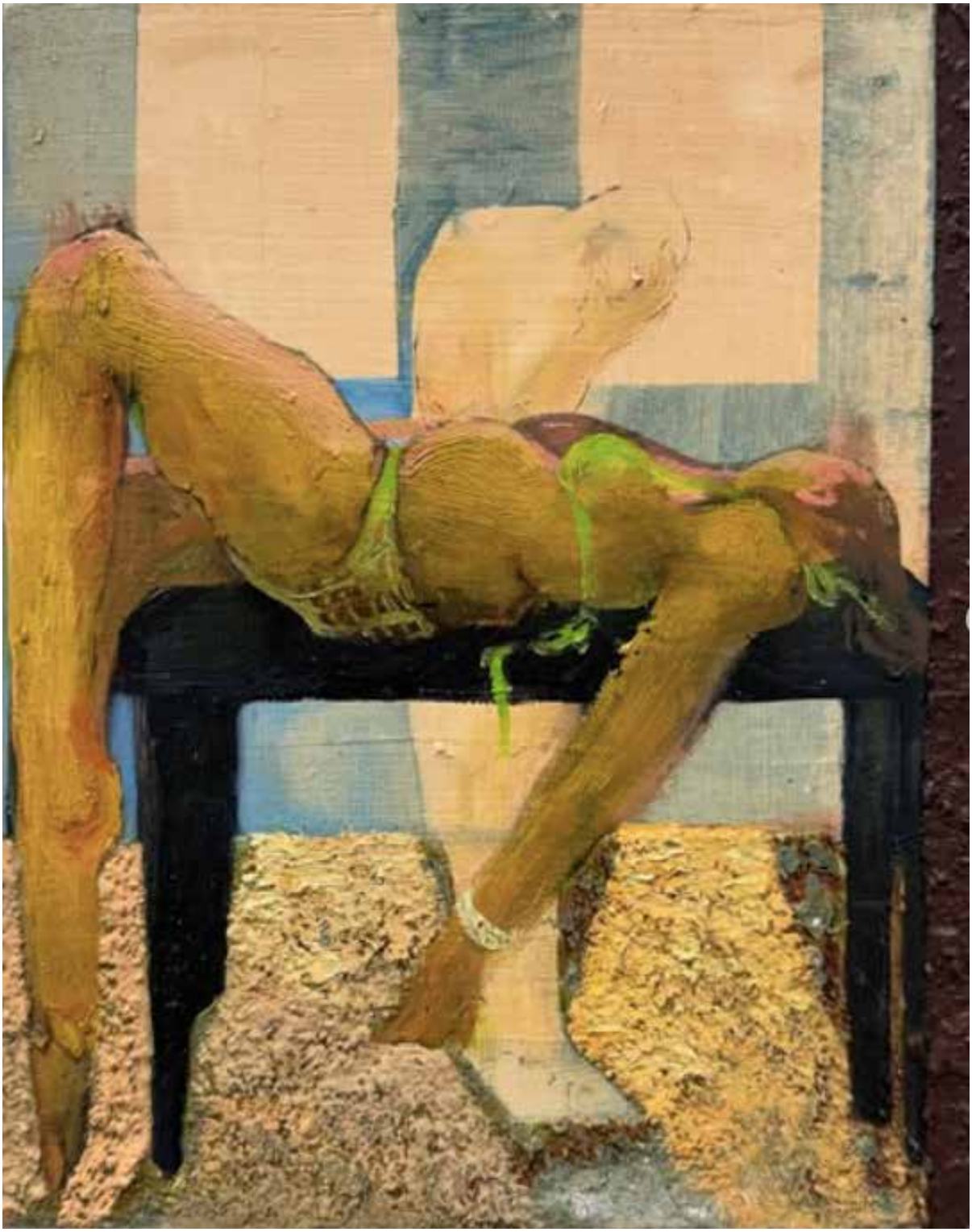
EXAMINE YOUR OWN RELATIONSHIP TO GRIEF

Difficulty sitting with chronic illness grief often reflects fear — fear of vulnerability, fear of losing health or fear of confronting ableist narratives. Minimising someone’s grief frequently reveals a limited tolerance for loss. Developing your own relationship with grief increases your capacity to stay present without dismissing or diminishing another’s experience - often showing up as toxic positivity.

No one person can be the only support. Chronic illness grief often intersects with trauma, medical stress, financial strain, and social isolation. Therapy, peer groups, disability-led spaces, and grief-informed counselling can provide context and containment. When access is limited, practical help with research or paperwork can make a tangible difference. Accessibility includes emotional infrastructure. You’re part of the support network, not the whole network.

You don’t need to fix chronic illness grief. You need to believe it, make space for it, respect rest, honour endings, and remain steady through consistency and compassion. Chronic illness grief is a living process of redefining a life in real time. Remaining present without demanding improvement becomes part of the stability that makes fulfilling connection possible. When grief is allowed its full expression, it doesn’t erase what’s changed, but it can open a steady path towards working with the life that still lives here.

Artwork by @chantalmika



Artwork by hy_steria.jpg + @endo.violence.collective
[Fourth Idea Studios]

Dos & Don'ts

(Problematic Phrases And Behaviours)

This section looks at various behaviours and things we often hear from friends that aren't appropriate or can be hurtful. We break down the reasons why not to say or do certain things and offer alternatives. We hope you find it useful!

Artwork by
@juliamaddison

DON'T SAY
'I can't wait to do X with you again when you're better.'

This can make it feel as though your relationship is on pause until the person is 'fixed.' It can suggest that you're only able to connect when they can participate in certain activities rather than valuing them as they are now. Chronic illness often comes with huge pressure to recover and to spend all available time, money, and energy trying to 'get better'. Not doing so is frequently framed as a personal failure or a lack of effort.

For chronically ill people, illness doesn't just blow over. Even when recovery is possible, it may take months or years and some people will never fully 'get better.' Hearing this phrase can feel like a friend has quietly decided to wait it out instead of meeting them where they are. Stop trying to make plans with a version of them that doesn't exist. Try to meet them where they are now.

You could even suggest an alternate way of doing X – find out what it is about X that your friend enjoyed before they were sick, and try to recreate that experience in an accessible way. E.g. they liked going clothes shopping with you, so why not offer to go to theirs and look at clothes together online? Maybe you used to go to the gym together, so ask what it was they enjoyed about that – if it was getting to move their body and spend time with you, then you could offer to come round, put their workout playlist on, and do some gentle movements or stretching. Or is there an accessible gym or exercise class you could go to together?

INSTEAD SAY
'I miss spending time with you. Would it feel okay if I popped over sometime soon, if you're up to it?'

'Is there any way we could find a way to do X, while meeting your needs? I know you miss going out for dinner, so why don't I come over and cook you a meal and serve it like a fancy restaurant?'

DON'T SAY
Have you tried X? (e.g have you tried yoga / going vegan / this new antibiotic etc.)

Please don't offer unsolicited medical advice. Trust that we know a lot more about our illness and the treatments available to us than you do. It's what we spend our whole life thinking about. It's unlikely that a 'miracle' supplement you've seen on social media or a new medicine that a friend of a friend is taking is going to be much help. Unsolicited medical advice is usually draining and frustrating. Do not try to 'solve' the problem for them.

If you genuinely have some possible insight (e.g. a relative with the same condition) don't jump to suggestions, but ask first: 'I know someone with the same condition. Perhaps I could put

Artwork by hy_steria.jpg + @endo.violence.collective
[Fourth Idea Studios]

you in touch with them'. Accept the fact that you don't know the answers and listen to the actual people with chronic conditions.

INSTEAD SAY:
'I know things have been difficult. I don't know the details, but if you would like to talk about it I would welcome the conversation'

OR just simply: *'I know you're doing everything you can'.*

DON'T SAY:
'Have you been to the doctors? There must be something they can do?'

A lot of chronically ill people stop going to their GP / doctors because they have never actually been helped by a doctor that wasn't a specialist (often private), or they have run out of avenues of treatment that a GP can offer. It's exasperating to be told to go to the doctors when you've already been so many times, and either: a) you've run the full gamut of tests and referrals so there is nothing more they can do, or b) it's amounted to nothing besides medical gaslighting and a sense of hopelessness. Remember that a GP is a General Practitioner—they do not usually have specialist knowledge. Chronic illnesses, however, are often complex and require specialist input.

There is also often significant stigma and lack of awareness around many chronic conditions, including disbelief that certain conditions even exist. Healthcare professionals are not exceptions to this. Your friend has likely had experience of doctors not believing them or mistreating them. They are even more likely to have experienced this if they are a woman, person of colour, LGBTQI+ or neurodivergent. Many chronic conditions go hand in hand with other chronic conditions, and it's common that the more diagnoses we have, the less we are believed. All of these things make it difficult for us to go to a doctor and trust we will be taken seriously—we may be at a point where we no longer see the use in going. Your friend has definitely tried going to the doctors.

INSTEAD SAY:
'I'm sorry things haven't been improving. I'm sure you're exhausted from the effort of trying to seek help and manage your condition.'

'Would it be helpful if I did some research for you? I can understand that it's overwhelming for one person to navigate everything'.

Left artwork by @telltailpdx
Right artwork by @mowandmolly

SIDENOTE ON UNSOLICITED ADVICE

We are all experts on our own conditions, this has only come from diligent independent research. We all have access to the same internet / resources and it means so much when people take the time to learn about our illnesses.

This is a great way to show up for your chronically ill friend. Learning about our illnesses and understanding the complexity of treatment and/or recovery will make it much less likely for you to say unhelpful things.

DON'T SAY:
Are you getting better?

Time does not heal all things. Chronic illness isn't linear. Someone might stay unwell for years, get worse, fluctuate unpredictably, or never 'recover' at all. Sometimes there is no rhyme or reason to the peaks and troughs of chronic illness, so try to avoid thinking in a very linear way about illness or believing there is always a cause and effect. Asking if they're getting better assumes improvement is inevitable and puts pressure on them to move towards wellness which may simply not be possible.

If a condition is life-long, 'getting better' isn't the framework you should be using. Focus on how they're feeling right now. And remember, 'better' is loaded. You might mean 'better than last month,' but it often comes across as if people are expecting us to have had a miraculous recovery.

INSTEAD SAY:
How are you doing at the moment? Would you like to talk about it?

DON'T SAY
"Are you better now?" (after your friend has received treatment or a new medication)

Of course you hope the treatment helped—so do we! But treatment isn't a magic fix. Sometimes it doesn't work. Sometimes it makes things worse. Often it comes with brutal side effects. It can be devastating to pin your hopes on something and end up in the same place or worse off than before.

Being asked *'are you better now?'* can feel like a spotlight on that disappointment. It forces us to say 'no' again and again which is incredibly disempowering. It can also lead us to feel pressure to bend the truth ('um, a bit better, yeah') to save ourselves from making you uncomfortable that the answer is no.

And if we look brighter or manage something we couldn't last time please don't assume that reflects our overall health. Appearances are unreliable. We know you're asking because you care. But trust that if we're improving / a new treatment has helped, we will tell you.

INSTEAD SAY:
'How are you feeling now you've had X treatment?' or 'How is X treatment going? Would you like to talk about it?'

Please do not do any of the following:

DON'T EXCLUDE YOUR DISABLED FRIEND FROM UPDATES / ISSUES IN YOUR OWN LIFE

Avoid withdrawing or stopping sharing your life with a friend because you think their problems are 'worse' or you don't want to add to their load. **When people stop sharing it doesn't protect us, it *isolates* us.** Many chronically ill people experience friends quietly pulling away under the assumption that we can no longer offer support or handle other people's issues.

No one wants a one-sided friendship centred only on illness or hardship. Your friend who is ill is still the same person they were with the same empathy and need for connection as you. While it's important to be mindful (for example, not complaining about being hungover to someone with chronic fatigue) sharing things like relationship struggles, work stress, or simply having a bad day is usually okay. Being treated like a burden, or made to feel as though you only take and never give can be deeply damaging, especially when chronic illness has already taken so much of your identity. We still want to be involved in other people's lives. Shielding us from updates or struggles in your own life can unintentionally reinforce the idea that we are fragile or helpless. We want to be included, not tiptoed around.

DON'T ASK THEM TO DO THINGS THAT THEY CAN'T DO

It is exhausting having to reiterate that you cannot do x y or z thing because of your limited capacity. Having to do this over and over again triggers feelings of helplessness, ultimately making that person feel more disempowered and like socialising is just out of the realm of possibility. For example - there have been countless times where we have reached out to a friend saying we need company or support or are generally feeling lonely and friends often respond with an invite to a party or a pub outing with a group of friends. This is not helpful. If we are not able to do these things (which most of the time we are not not) we will end up feeling more lonely than we did to start with.

As stated previously; as an 'able-bodied' person you have the resources to fit into their world, they do not have the resources

Artwork by @june_sniff

to fit into yours. This isn't to say never invite them to anything ever again! It's lovely to be invited to things even though we usually won't make it. But responding to a request for support or company by inviting them to a social event that will be physically exhausting or just not possible for them probably isn't the way to go and will signal to them that you aren't a person they should reach out to for support.

DON'T STICK YOUR HEAD IN THE SAND BECAUSE YOU DON'T KNOW WHAT TO SAY.
Do some research, make time to support your friend, ask them what they need.

DON'T ASSUME THAT YOUR FRIEND RECEIVES ENOUGH SUPPORT FROM OTHER PEOPLE
Often everyone assumes other people are doing the work to support someone but that isn't necessarily the case. Ask them if they need support - it's absolutely fine to ask what support means and looks like to them if you have no idea where to start. Especially early on in the development of a chronic illness, your friend might not yet know what kind of support would help them most. Brainstorming together can be really helpful

DON'T ASSUME THAT BECAUSE YOU HAVEN'T SEEN THEM AT SOCIAL EVENTS THAT YOU'VE JUST 'DRIFTED APART'
Your friend needs you to put effort into maintaining a relationship with them. Many social events are no longer accessible to them leaving them more isolated. They may no longer have the resources to fit into your world but you have the resources to fit into theirs.

DON'T MAKE THEIR ILLNESS ABOUT YOU
You may experience your own grief when someone you love becomes disabled or sick and you may find it difficult to cope with the ways in which your relationship has been impacted. This is valid! But don't make it their responsibility to support you through it. Speak to a friend or partner or therapist.

DON'T EXPECT BIG FAVOURS
Or effort from someone currently going through a health crisis. It can be very jarring when someone knows that things are really difficult on our end and yet only reach out when they want something.

DON'T AMBUSH SOMEONE AT A SOCIAL EVENT WITH QUESTIONS ABOUT THEIR HEALTH IN DETAIL.
It's probably taken a lot out of them to get there and the last thing they want to do is relive trauma for other people's curiosity.

DON'T ASK FOR HEALTH UPDATES TOO FREQUENTLY
Things have probably not changed much since you asked 3 days ago, and they don't want to keep repeating themselves about their condition all the time. Let's talk about something else!

DON'T MAKE THEM FEEL GUILTY ABOUT HAVING TO CANCEL PLANS.

Artwork by @KYRIANNA

Active Support

One of the worst things about becoming chronically ill is the isolation you experience. We all crave human connection, we literally need it to stay sane. When you can't get out and about independently and lose the capacity to do activities it can feel like you're excluded from the world. Feeling like a zombie stuck at home or in bed, forced to watch the world moving onwards without you is a very common experience. There are lots of small and big things you can do to help combat the loneliness a friend with a chronic illness may be feeling, some of which will also be of great physical or mental help for them.

Active support you can offer

IF YOU ARE ABLE TO COME TO THEM IN PERSON YOU COULD:

- Offer to do some chores for them (tidying, hoovering, laundry etc). If your spoonie friend has an energy-limiting illness or mobility issues, chores might use up all of their energy for an entire day leaving no energy for doing nice things that would be more enriching to their life.
- Do a shop for them.
- Offer to accompany them to appointments.
- Offer to cook a meal for them / bring frozen meals to their house to stock up their freezer.
- Ask if there's anywhere they'd like to go but wouldn't be able to without a carer or companion, and see if you can join them - e.g maybe they'd love to go to an art exhibition but would need to be pushed in a wheelchair.
- Offer to do a physical activity with them that they have capacity to do but may struggle to incentivise themselves to do solo; a short walk, yoga, simple stretches, physio exercises they have been procrastinating etc.

IF YOU CAN'T COME TO THEM IN PERSON YOU COULD:

- Offer to watch a film remotely together - there are services you can use to do this or you can just get them on a call and sync the movie up.

- Buy them an uber somewhere so they can do something they might otherwise be unable to do.
- Check in via phone call.
- Write them a letter (just don't expect an immediate response).
- Organise for everyone in your friendship group to anonymously add £5 to a pot each month that you send on to your chronically ill friend, so they can afford to get an uber to see you / come to that meal out / cover their grocery bill. (get consent before you do this! Not all chronically ill people will have their finances affected by their illness, but many will)
- Ask if they need someone to do some research for them. Becoming chronically ill opens up an entire world of endless supplements, 'off-label' treatments, and different possible medications. They are likely overwhelmed by the possible options and having someone spend an hour on Reddit to work out what supplements might help can be incredibly useful. Researching their illness also allows you to understand their reality a little better.
- Offer to do some virtual tasks for them that would take up their spoons — draft an email they've been meaning to send, phone to make an appointment for them, help them organise their calendar/diary, book a trip somewhere, buy tickets for an event for them, etc.

IF YOU HAVE A CAR YOU COULD:

- Ask if there's anywhere they would like to go
- Offer to take them out into the world (Into nature, to parks, gardens, the beach, moors...)
- Look up some places that are accessible for your friend's needs (e.g. a sensory-friendly theatre performance; a café with step-free access)
- Take them to the supermarket, or somewhere else they need to do an errand (post office, clothes shop, bank, etc)
- Just take them on a drive with no destination or activity, or to a place you can stop and roll the windows down, if they just need to get out of the house.
- If your friend receives PIP (benefits for sick and disabled people), they're automatically eligible for a Blue Badge, which allows parking closer to museums, heritage sites and galleries, making cities much more accessible. It also benefits whoever is driving! Plan a day trip and skip the commute and queues. Blue Badge holders can also register for a 100% Congestion Charge discount, even if they don't own or drive a vehicle.

ACCESSIBLE ACTIVITIES:

- Crafting (Collage, Embroidery, drawing etc)
- Games night / game day (board games, video games, quizzes etc)
- Watch a movie (sometimes someone might not have the energy to chat but it's still nice to have company)
- Offer to body double with them (i.e do your own things but in the same room)

‘Sleeping Beauties’ (1868)
Felice Beato, 1832-1909

Courtesy National Gallery of Art, Washington

- Read out loud to them
- Listen to music together

OTHERS WAYS OF PROVIDING ACTIVE SUPPORT:
Check-in with how they're doing when you're hanging out. They might be getting really tired and need you to leave but don't know how to say that without sounding rude. They might be sitting in a seat that's painful for them, but they don't want to cause any problems by asking to move. Ask how they're feeling, are they comfortable here, do they need anything?

Drop them a message the next day or a few days after seeing them. For some chronically ill people, a social engagement can cause a flare in symptoms. It can be hard to know your friends moved on from your quick catch up and continued with their lives while you are stuck in bed for the next few days. A check-in a day or two later helps them feel not forgotten, and can help you better understand how seeing you impacted their symptoms. This can help you both think about making events more accessible.

Help them get their accessibility needs met, so they can take part. Can you help your friend get the help they need? Can you ask for someone to get a chair with the right kind of back support, so they don't have to? Can you ask where the accessible toilet is? Can you find out other accessibility information about a venue? Can you explain their accessibility needs to others (with permission) so they aren't constantly explaining themselves? Can you research accessible activities/classes/places? They're probably used to having to ask for assistance themselves, so it would be great if you could be one step ahead.

Be conscientious about their health information and schedule so they don't have to repeat themselves. If you're messaging on social media, use the chat search (e.g. "appointment") before asking about dates you've already been told. Don't rely on memory, write things down and add important dates to your calendar so you know when to check in. This can include anniversaries of accidents or illness, when they may be struggling (see Chronic Illness Grief). Remembering these details means a lot.

Organise a social event at their home. This sounds so simple and obvious but more often than not chronically ill people have to coordinate the logistics of every social activity to make sure that it will be accessible for them. If they want people to come to them, they usually have to organise that themselves and chasing people up to organise things takes a lot of energy. You could get some people together to come over to watch a film or get a takeaway at theirs. Organising this for someone would be such a godsend and would allow them to conserve more energy that can then be used to enjoy the event you organise.

Tell them how they light up your life. Tell them what they mean to you, as they are now. It can be incredibly moving to be told the positive things that make you glad to be our friend, to have some-

one highlight to us all the ways we're still valued and loved, especially when we feel we've lost so much of our personality and life and passions to illness, when our worth feels tied to those things we no longer have or can no longer do.

One of the biggest things you can do is work on having more capacity to sit with uncomfortable feelings and situations without running away or trying to solve the problem.

SAY THINGS LIKE:
'I don't know how best to support you, what can I do?'

'I'm really glad you're here, it means a lot to see you.'

'I value you and our friendship'

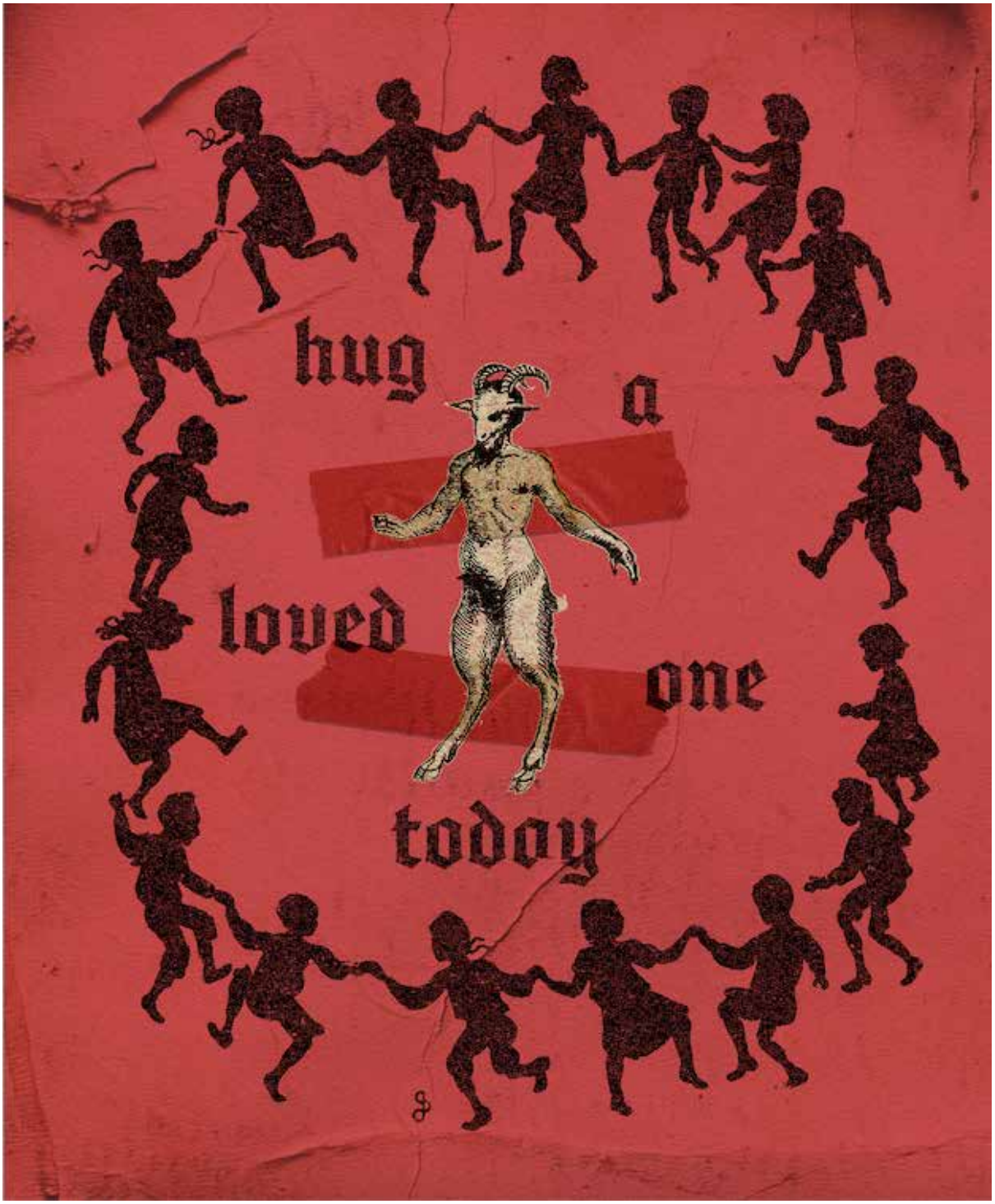
'If you can't make it to plans we make I will always understand'

'Feel no pressure to reply to this right away'

'I believe you'

'You're doing your best and I'm proud of you'

Artwork by @ paper crisis



Rebuilding Connection:

REACHING OUT TO A FRIEND YOU'VE AVOIDED (CONSCIOUSLY OR SUBCONSCIOUSLY)

If you've avoided / ignored / neglected / forgotten a friend that has been absolutely going through it in terms of health and you now want to reach out and offer support you absolutely can. But please make sure you are doing this in an appropriate way. Before we get into how to go about rebuilding connection, here are some things to keep in mind.

POWER DYNAMICS

Chronic illness can introduce difficult power dynamics into relationships. Sometimes we depend on friends or family for things we physically cannot do ourselves. For example cooking meals, doing food shopping, or helping us get to appointments. When someone holds that kind of practical power in our lives, it can feel incredibly risky to challenge their behaviour, even when it's hurtful.

We may tolerate things like a lack of empathy, minimising our suffering, or unreliable support because we're afraid of damaging a relationship we rely on. When your basic needs depend on someone, protecting that relationship can feel more urgent than protecting your own sense of dignity or self-worth.

UNRELIABILITY

For many chronically ill people, unreliable friendships become something we simply cannot afford.

Reaching out, explaining our needs, or making plans takes energy and when someone repeatedly lets us down or doesn't remember the needs we have already explicitly named, that energy is wasted. Over time we eventually learn not to accept crumbs of support from friends who consistently fail to show up.

When people we trusted disappear during illness or flares in illness, it can be incredibly damaging to our sense of self. It's hard not to internalise the message that we are a burden or that our needs are too much. Having to repeatedly explain our situation or convince friends to care can feel humiliating. No one should have to beg their friends for compassion.

RECALIBRATING SUPPORT SYSTEMS

Chronically ill people can end up constantly recalibrating their support systems.

Over time we learn what different people in our lives are realistically able to offer. Some friends may be great at emotional support, while others may be better at practical help like bringing food during a flare. Some people may not be able to provide support at all. Each time someone lets us down, we often have to reassess what we can expect from them and adjust our expectations accordingly. When someone we thought we could rely on suddenly withdraws, we have to go back to the drawing board and rethink our support network again. This process is exhausting.

Clear communication can prevent a lot of this uncertainty. For example, saying something like:

"I care about you, but work is really intense right now and I need to focus on that for a while. I'll check back in in a month."

This gives clarity and reassurance, rather than leaving someone to interpret silence or distance as abandonment.

DON'T OVERCOMMIT

Only commit to what you can realistically offer. Overpromising support and then disappearing is more painful than doing nothing. It can also leave us in difficult or dangerous situations. For example if someone makes a commitment to make us dinner and then bails or disappears we might have to go without food that evening. Be honest about your limits from the start. If you know you only have capacity to check in occasionally, say that. Being realistic about your capacity helps build trust and prevents further hurt.

Steps to rebuild

We have all experienced feeling as though a friend has totally abandoned us or ignored our needs because it didn't suit them or they just forgot. This can be really hurtful and disempowering and compound experiences of powerlessness and isolation that are already brought on by chronic illness.

When people feel guilty for avoiding or neglecting a friend in need they often do one of two things:

- Message them like nothing happened ('Hey! Long time no see!')
- Continue to avoid them out of guilt.

Both responses can make reconnection harder.

Once we have learnt that this friend isn't someone who will make any effort to fit into our lives we will quietly grieve that relationship, the bond we thought we had and the future we imagined with that person. As the saying goes; when someone shows you who they are; believe them. Becoming chronically ill and/or disabled forces us to come to terms with a lot of hard truths. This includes coming to terms with the fact that people who we thought loved us and would always be there for us just don't care enough. Many people aren't willing to push past the awkwardness of engaging with disability and show up when it is no longer easy and fun for them.

When one of those people then randomly pops up months / years later with a 'hey how are you? Let's hang out soon!', it can be really jarring. It brings up a lot of feelings. Resentment is definitely one of them. Why now? We would have given anything for that person's support a year ago or when we last reached out to ask for help. It can feel really irritating to imagine that someone has suddenly remembered we exist or are reaching out to dissuade their own feelings of guilt after having neglected us. If you want to reach out after a long period of silence it is important to name your absence.

POTENTIAL OPENINGS TO RECONNECT WHILE NAMING YOUR ABSENCE:

- 'Hey I feel like I've been really absent and would like to be more present / involved in your life again'
- 'I realise my absence may have added to what you were already dealing with. I'm really sorry if that's the case and I would like to acknowledge it.'
- 'I'm sorry I haven't reached out, I haven't known what to say and was afraid of saying the wrong thing but I miss you and would love to see you in a capacity that suits you'.
- 'I realise I wasn't around when you needed people the most, and I'd like to change that going forward'
- 'I can imagine that the silence on my end has been really difficult for you, would you be open to talking about it so I can understand how to do better?'

- '...feel no pressure to respond to this right away'

We aren't looking for a dramatic declaration of your neglect and your unwavering commitment to do better and never let us down again. We just need to know that you understand that your behaviour or lack of support has had an impact. When you're chronically ill it's easy to feel like you're going mad. Doctors can't treat you, benefits systems are set up to deny support for invisible illnesses and friends constantly disappear. We need to feel seen in our relationships.

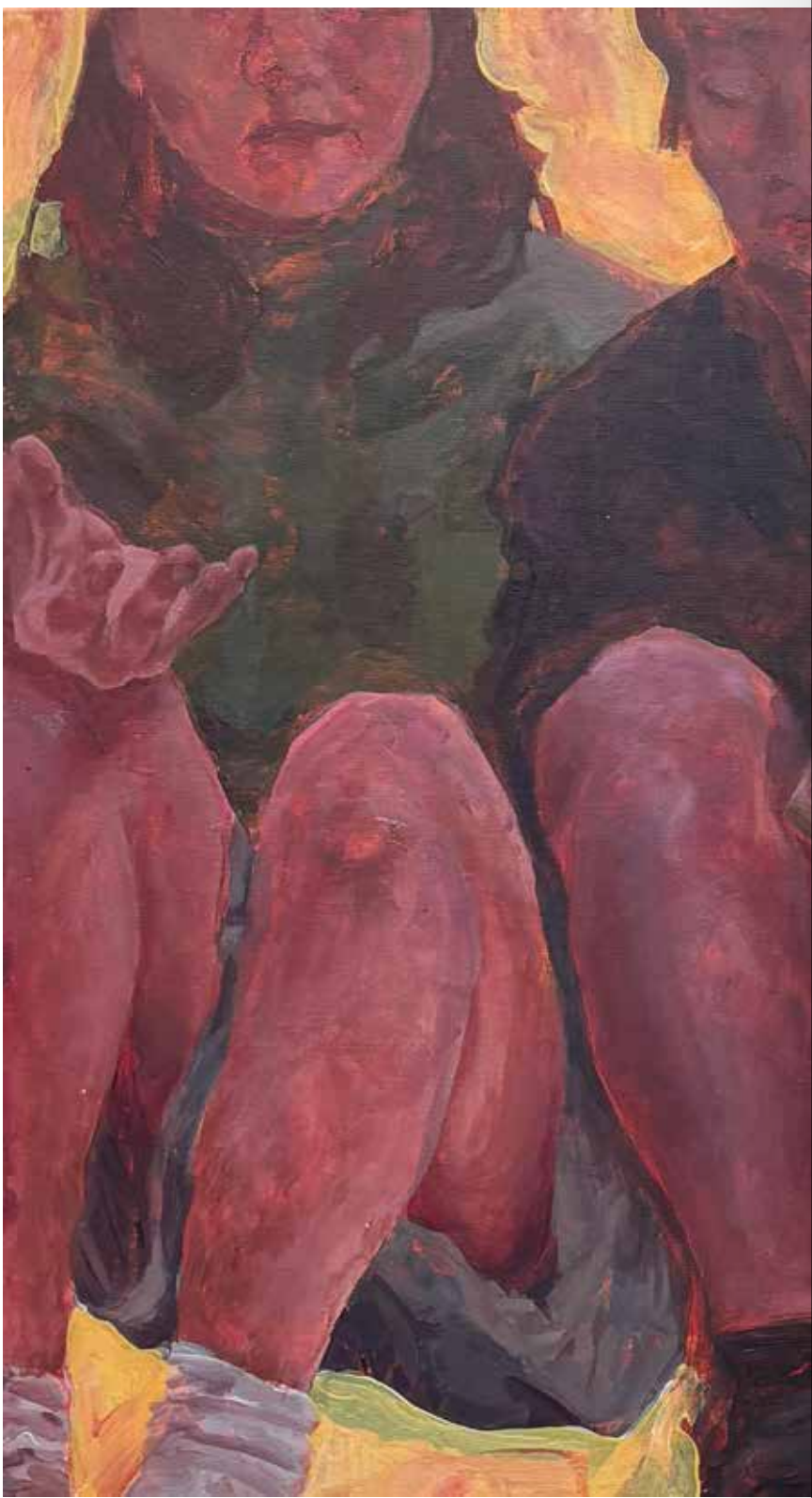
WHEN EFFORTS TO REBUILD AREN'T ENOUGH

Even with all the right phrasing, even when you're truly remorseful and genuinely want to rebuild the relationship, your friend might not want to reconnect with you. When someone who we thought would always be in our lives abandons us, it really hurts. In many ways it is a form of heartbreak or can be experienced as a bereavement. By the time you've realised the impact of your actions we may have already done the work to grieve the relationship.

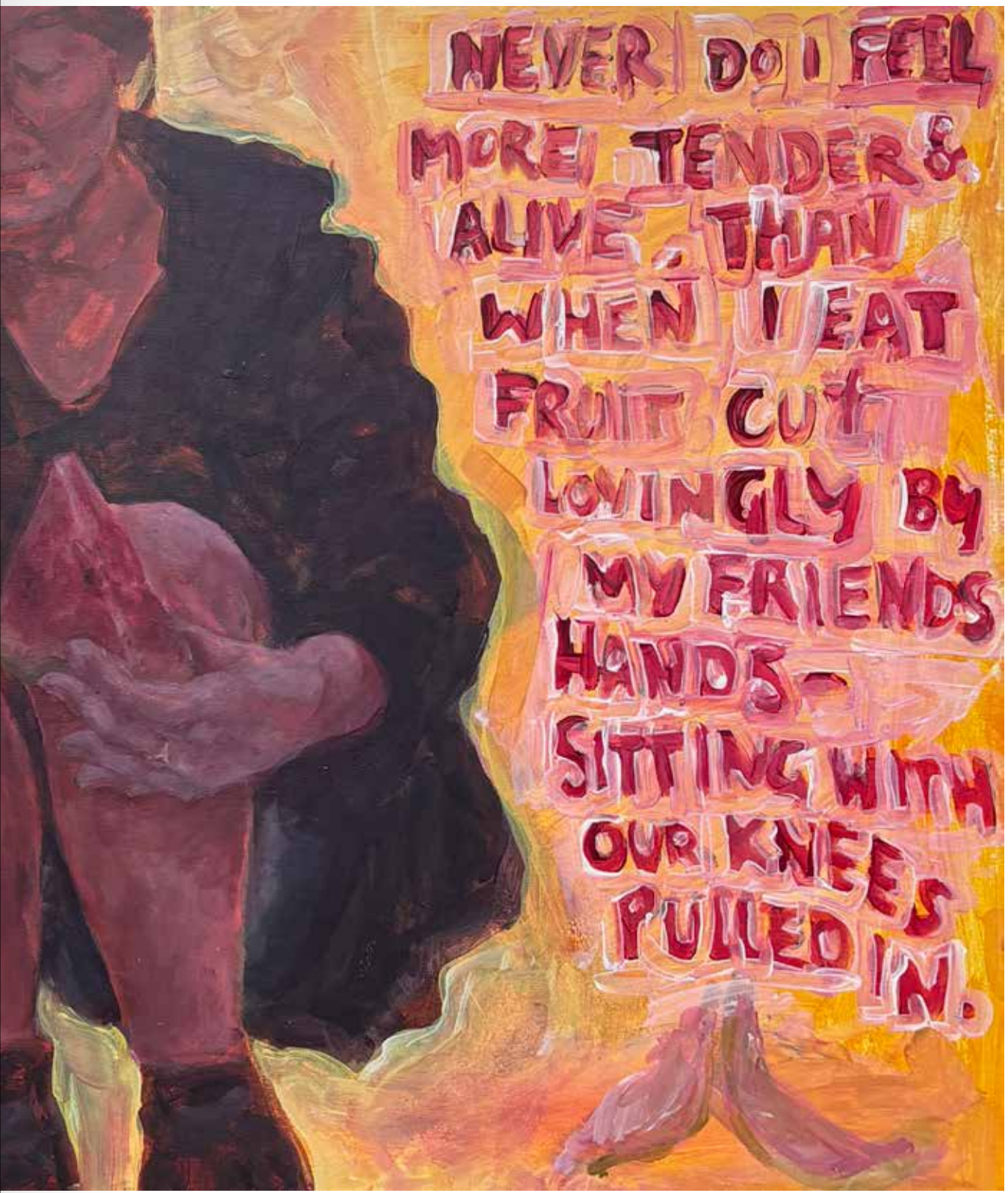
Don't expect your friend to immediately forgive you or for things to just "go back to normal". It might be too little, too late. As upsetting as this eventuality might be, we hope that you can learn from the experience and not make the same mistakes in future, if you have another friend who becomes chronically ill or disabled.

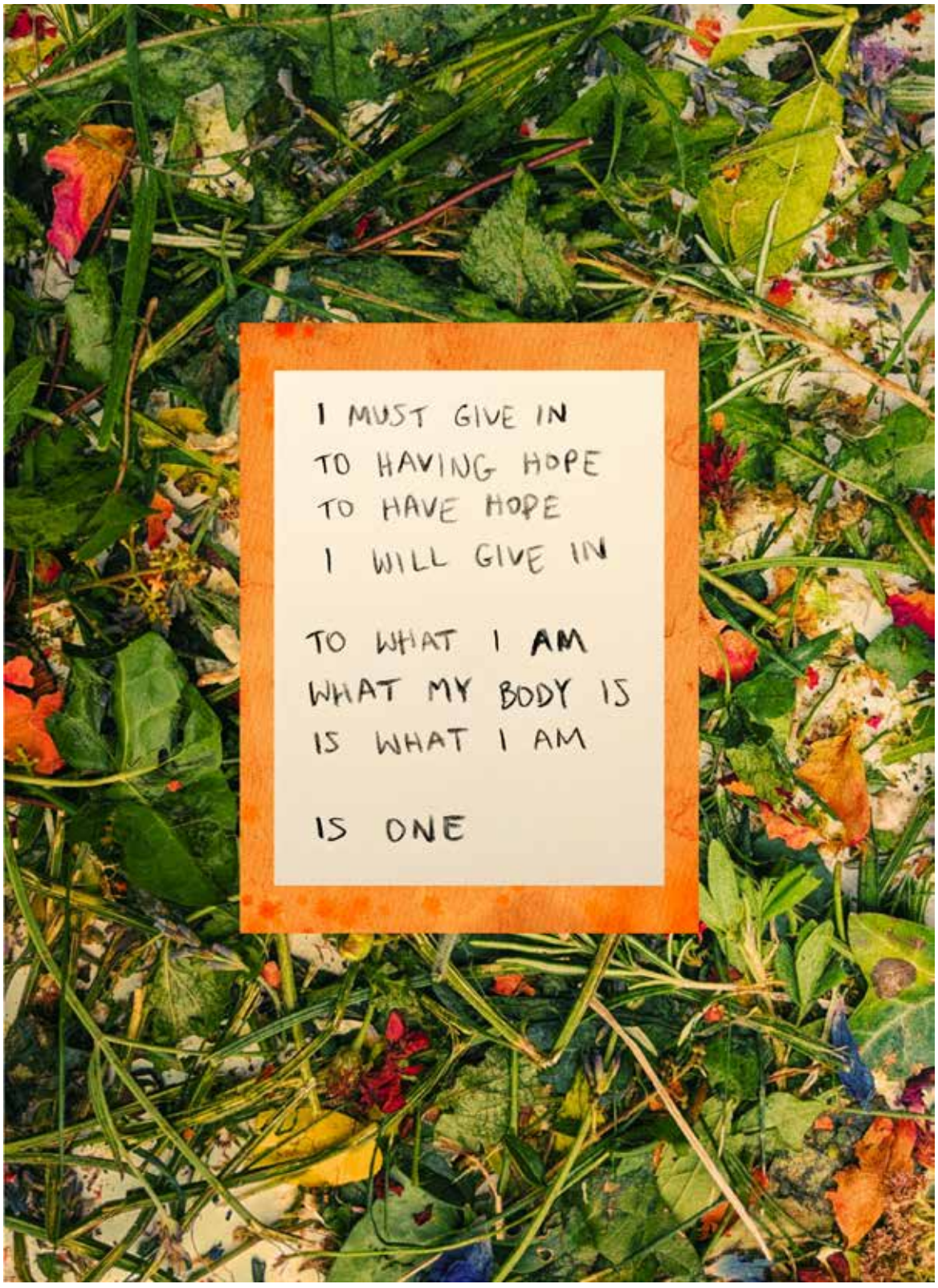
Artwork by @bondoso_bandido

Artwork by @sunthruthewindow



DO YOU NEED ME TO SPELL IT OUT?


NEVER DO I FEEL
MORE TENDER &
ALIVE, THAN
WHEN I EAT
FRUIT CUT
LOVINGLY BY
MY FRIENDS
HANDS -
SITTING WITH
OUR KNEES
PULLED IN.


I MUST GIVE IN
TO HAVING HOPE
TO HAVE HOPE
I WILL GIVE IN
TO WHAT I AM
WHAT MY BODY IS
IS WHAT I AM
IS ONE

Thank you for reading

We've come to the end of the guide. There are so many things left unsaid about chronic illness and the breakdown of relationships but hopefully you feel better equipped to ask useful questions and provide support.

At times it can feel incredibly frustrating to have to explain how to be a friend—hence the title 'Do You Need Me To Spell It Out?' We have all lost people we didn't think we would lose and had to repeat things that we didn't think would ever need saying.

But we have tried to create a non-shaming informative guide to help able-bodied allies better understand their chronically ill and disabled friends. We hope that this resource will save time, energy and hurt for other people struggling with their friendships. Thank you for taking the time to read it.

Artwork by Emily Raven-Baker

Further Reading

SHORT ESSAYS
(HALF AN HOUR OR LESS TO READ)

Sick Woman Theory
by Johanna Hedva
https://www.kunstverein-hildesheim.de/assets/bilder/caring-structures-ausstellung-digital/Johanna-Hedva/cb6ec5c75f/AUSSTELLUNG_1110_Hedva_SWT_e.pdf

Six Ways Of Looking At Crip Time
Ellen Samuels
https://dsq-sds.org/article/id/1565/

Access Intimacy: The Missing Link (Mia Mingus)
https://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/

10 Principles of Disability Justice (Sins Invalid)
https://sinsinvalid.org/10-principles-of-disability-justice/

On Being Ill
https://thenewcriterion1926.wordpress.com/wp-content/uploads/2014/12/woolf-on-being-ill.pdf

BOOKS AND PLAYS

The Shape of The Pain
Chris Bagshaw and Rachel Thorpe

Disability Visibility
A Collection of essays edited by Alice Wong

The Body Is A Doorway
Sophie Strand

Some Of Us Just Fall
Polly Atkin

Care Work: Dreaming Disability Justice
Leah Lakshmi Piepzna-Samarasinha

How To Tell When We Will Die
Joanna Hedva

Black Disability Politics
Sami Schalk

This Is Body Grief
Jane Mattingly

The Anti-Ableist Manifesto
Tiffany Yu

Ill Feelings
Alice Hattrick

Sick Magazine

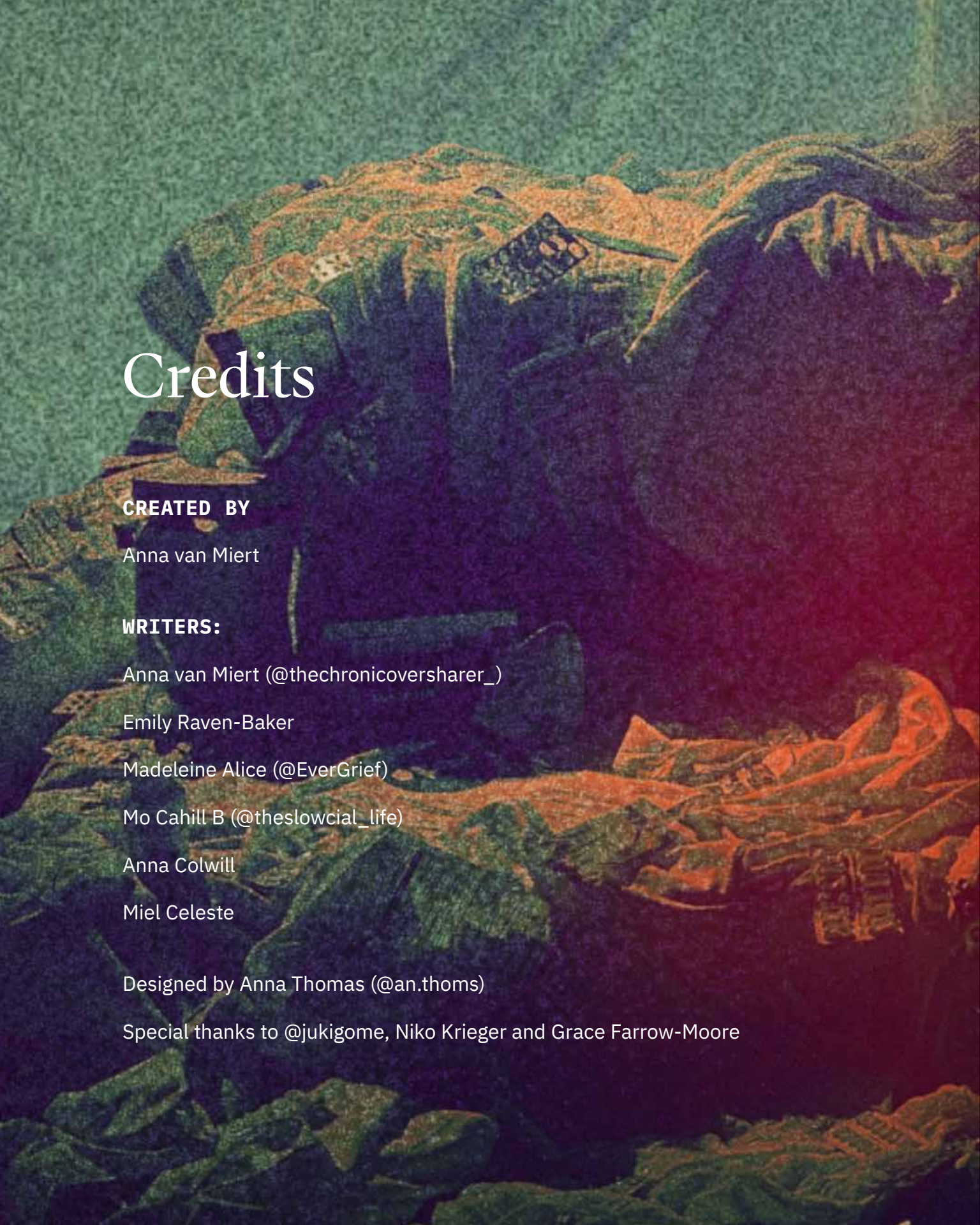
Ache magazine
(Feminist writing on illness, health, bodies and pain)

Body Friend by Katherine Brabon

Out Of Sorts
The Remote Body

Crip Authorship — Disability as Method
Edited by Mara Mills and Rebecca Sanchez

Being Seen
by Elsa Sjunneson



Credits

CREATED BY

Anna van Miert

WRITERS:

Anna van Miert (@thechronicoversharer_)

Emily Raven-Baker

Madeleine Alice (@EverGrief)

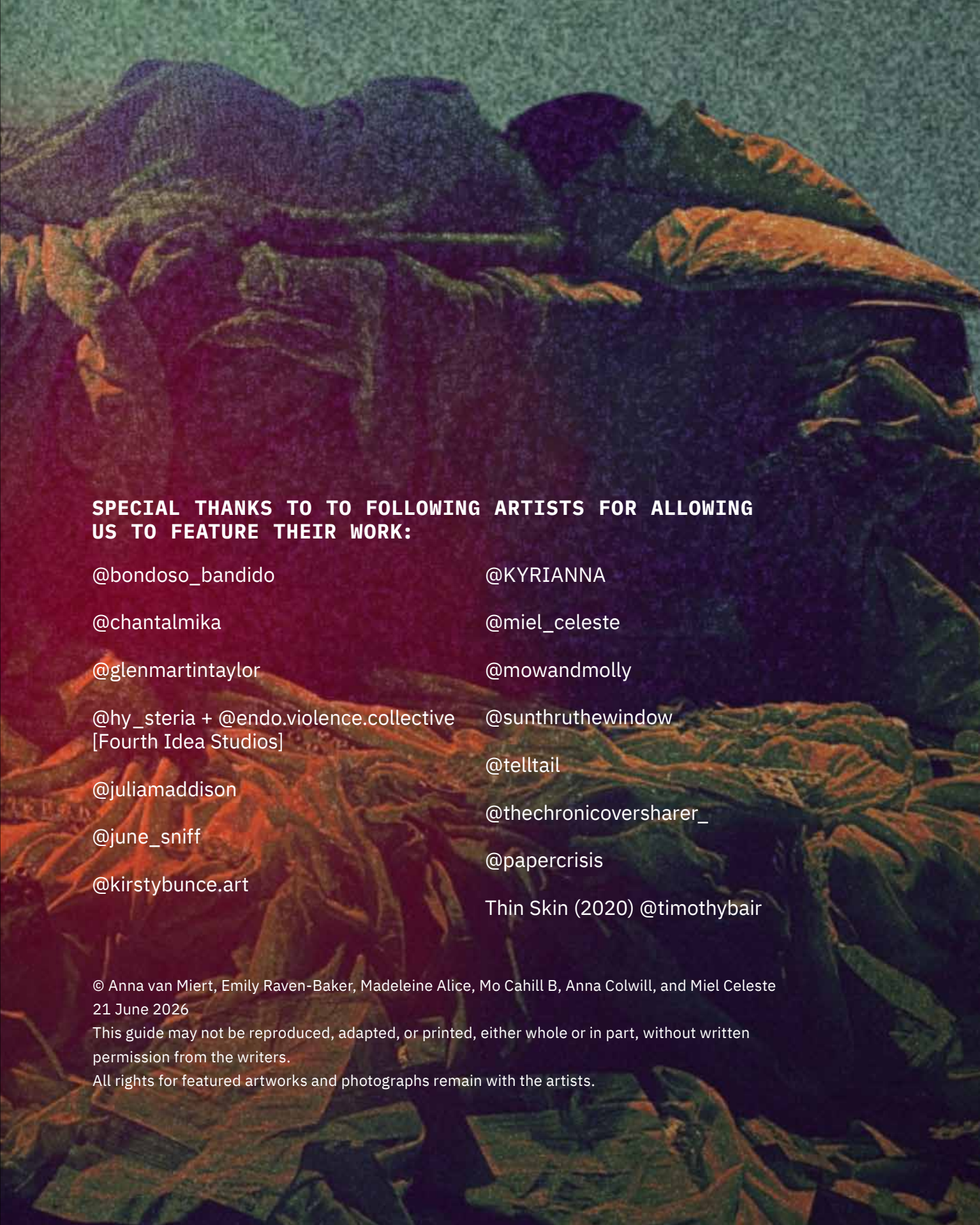
Mo Cahill B (@theslowcial_life)

Anna Colwill

Miel Celeste

Designed by Anna Thomas (@an.thoms)

Special thanks to @jukigome, Niko Krieger and Grace Farrow-Moore



SPECIAL THANKS TO TO FOLLOWING ARTISTS FOR ALLOWING US TO FEATURE THEIR WORK:

@bondoso_bandido

@chantalmika

@glenmartintaylor

@hy_steria + @endo.violence.collective [Fourth Idea Studios]

@juliamaddison

@june_sniff

@kirstybunce.art

@KYRIANNA

@miel_celeste

@mowandmolly

@sunthruthewindow

@telltail

@thechronicoversharer_

@papercrisis

Thin Skin (2020) @timothybair