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# Mad Workplaces

A commonsense guide for people with 'mental illness' on how to navigate the workplace



This is the eighth in a series of publications written by and for mental health consumers by Our Consumer Place, a groundbreaking mental health resource centre run by people with a diagnosis of "mental illness" (consumers). Our Consumer Place (**www.ourconsumerplace. com.au**) is funded by the Victorian Department of Health and auspiced by Our Community (**www.ourcommunity.com.au**). We offer information and advice to individuals and groups who provide or are thinking about providing consumer-developed initiatives.

## Mad Workplaces: A commonsense guide for people with "mental illness" on how to navigate the workplace

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Our Consumer Place PO Box 354 North Melbourne VIC 305 I Email: service@ourconsumerplace.com.au

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## Mad Workplaces: A commonsense guide for people with "mental illness" on how to navigate the workplace

(Our Consumer Place resource centre booklet eight)

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#### **Dedication & acknowledgements**

This booklet is dedicated to our colleagues at Brook RED (**www.brookred.org.au**) and Voices Vic (**www.prahranmission.org.au/hearing\_voices.htm**), two pioneering organisations run by and for people with lived experience of "mental illness". Each of these organisations is building healing communities, while practising innovative and grounded ways of managing "mental illness" in their workplaces. We believe these organisations are changing the world, the mental health system and workplace practices for the better.

#### Managing "mental illness" at work: Let's go there

Managing "mental illness" at work is not an easy topic, although we often want to believe that it's easier than it is – or harder than it needs to be.

There is no simple, one-size-fits-all, 10-point list of do's and don'ts. Most of us would love to have easy answers to hard questions, but we take a very different (and, we think, more sensible and more useful) approach in this booklet. We know from lived experience that generic approaches are usually ineffective, tend to white-wash over the hard stuff and are often irritating into the bargain.

While we acknowledge this is a genuinely tricky topic, we also know that there are skills, tools and ways of approaching the issue that are constructive and effective. And we know that the best knowledge, tools and strategies are those that are based on real life experience, not just good intentions.

Many of us who live with "mental illness" face complex barriers to meaningful, sustainable employment. Conversely, employing or working with a colleague who has "mental illness" can at times be confusing, frustrating and uncertain (including for those of us who also have "mental illness" ourselves!).

It doesn't have to be like this: if we as a community listened more deeply to what life is like for those of us with "mental illness", if we were all better able to have the necessary (and often difficult) conversations, and were more adaptable and flexible, "mental illness" in the workplace would be more than just "manageable".

In fact, we believe that intelligent management of "mental illness" in the workplace can transform work practices to create a more meaningful and sustainable workplace for everyone!

# Why this booklet's different (and should be read by everyone in your organisation)

This booklet is quite different from others on the topic of "mental illness" and the workplace.

For one thing, it's *not* another resource produced by well-meaning charities or experts, telling people with "mental illness" what's good for us (or why working is good for us).

It doesn't assume that we are "sick" while the rest of the workplace is "healthy". We're not interested in giving out patronising advice about the importance of having a positive attitude, getting up early, eating sensibly and taking your medication. We also won't dispense unhelpful statements such as "mental illness is just like diabetes".

Instead, we are offering up what we hope you'll agree is a realistic and useful booklet, one that is grounded in lived experience and willing to delve into the hard stuff.

It's been written collaboratively by people living with a diagnosis of "mental illness" (sometimes we call ourselves – or get called – "consumers"\*), so we know from experience what we're talking about. There has also been significant consultation with people who employ consumers and people with expertise in relevant laws and employment practices.

While we're clear in this booklet about the need for workplaces to change in order to give people with "mental illness" (actually, everyone) a chance to thrive, we know that there are challenges and difficult questions for all involved. So we're offering up a two-faced booklet, one side designed specifically for workplaces (and in that we include human resources departments, bosses, managers and colleagues), and the other designed for people with "mental illness".

Ideally, both consumers and those who work with us will read both sides of the book – and this will lead to true understanding.

As always, we offer this material in the spirit of take what you like and leave the rest.



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#### \*A note on language

In this booklet, we talk about "people with a lived experience of 'mental illness'". In current mental health policy, we often get called "consumers" - people who use/consume mental health services. There are also many consumer organisations who use this language (us, for example, at Our Consumer Place).

This language does not resonate for everyone - some of us use other words (such as "person with a mental illness" or "someone with bipolar", "psychiatric survivor" or even "mad person") and some of us don't want another label or identity to go along with our "mental illness" experiences.

It's a complex issue, and one that we talk about more on our website (www.ourconsumerplace.com.au/ glossary).

You may also notice that at times we place words or phrases (such as "mental illness") in inverted commas. We use these words because they are commonly understood, but by putting them in inverted commas we are acknowledging that not everyone agrees with their use - these terms are contested. For example, the idea of "mental illness" is not something that all consumers identify with - some will express sophisticated intellectual, political or spiritual critiques of this concept. Others find it profoundly useful. The term "carer" is also a term that for some consumers misrepresents the role of support people in their lives.

By putting these terms in inverted commas we are acknowledging and respecting the diversity of understandings among consumers without suggesting there is a "right way" to think about these issues. Again, there is more discussion on our website.



#### It's not all in your head

Many of us negotiate working while also living with a "mental illness". We do so in various different ways, depending on our temperament, environment and experiences. To get the most out of this booklet, we suggest you at least dip into the other side, or (better yet) read it in its entirety. There are some issues that we have only covered on the other side – for example, your rights in relation to privacy, bullying, discrimination, etc., as well as some of the "reasonable accommodations" you might explore in your workplace. We think that workplace issues are best approached from a position of understanding – so it may help to consider where your employer and colleagues are coming from.

We navigate many complex issues when it comes to "mental illness" and work: for example, how to decide whether to disclose and what to say; what rights we have and how we can realistically exercise these rights; workplace bullying and its relationship to 'mental illness'; toxic workplaces; and returning to work after an embarrassing "incident".

There are also many tools available to us that we might not know about – such as 48/52, advance directives and reasonable adjustments.

We haven't tried to cover everything in this small booklet – for example, we don't cover preparing for work, social enterprises, supports that are available for returning to work after an absence, workers' compensation or the interface between work and government benefits.

Also, while this booklet is relevant to people for whom being a consumer is an inherent requirement of the job (e.g. consumer consultant, consumer academic, peer support worker), it does not cover issues specific to those jobs. What we are offering is a consumer perspective on managing "mental illness" and work – a perspective that we hope will be useful both for those of us who work while living with "mental illness", and for those who work with us.

## To disclose or not to disclose: That is the question

#### Disclosure at a glance

- 1. Do I need to disclose? You are not legally obliged to disclose your 'mental illness' to your employer, unless it is likely to affect your work. (Check out the flip side of this booklet for information on discrimination, page 29, and privacy law, page 32.) Even then, you don't necessarily need to disclose your illness as such. You will need to consider the potential impact of your "mental illness" on your work, and provide enough information so that "reasonable adjustments" can be negotiated.
- 2. Should I disclose anyway? This is a personal decision, and there is no right or wrong answer. There are many things to consider in deciding whether or not to disclose, including both your work environment and your own circumstances.
- **3. What exactly would I disclose?** If you do choose to disclose, consider what would be effective disclosure. Telling your employer your diagnosis might seem like the most obvious approach, but it is not actually the most useful information.
- 4. In conclusion This is a complex and often tricky situation most of us navigate it to the best of our ability, and learn from experience.

In deciding whether to disclose mental health difficulties there are many factors to weigh up. It is important to think seriously about these issues because the consequences – either way – are very real and impossible to undo.



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#### **Reasons to disclose**

- If your "mental illness" is reasonably likely to affect your work, you will probably need to disclose (see the section on reasonable accommodations on the flip side of this booklet, page 33).
- Disclosure makes negotiating accommodations or supports easier (or possible!).
- Disclosure can remove some of the uncertainty for everyone involved.
- Sometimes disclosure is not really about "if" but "how" and "when", if it is obvious to colleagues or managers that "something is up".
- If you choose to disclose, disclosure can be on your own terms: you get to choose how, when, what and to whom you share. A carefully considered disclosure is preferable to an unintentional disclosure for example, if something just "slips out" when you are overwhelmed.
- If you have not disclosed, it can be stressful feeling that you need to hide what is happening for you.
- Disclosure can open up important conversations and learning for everyone involved.
- An effective disclosure often involves a consideration of what responses from the workplace are desirable; this then reduces the likelihood of ineffective responses.
- You may generally be an open person; non-disclosure may feel like secrecy or shame (although not everyone experiences non-disclosure like this).

#### Reasons not to disclose

- You may decide that you have nothing you need to disclose because your "mental illness" has no bearing or impact on your work.
- You may possibly encounter discrimination, harassment or bullying, including in unexpected places (for example, in otherwise "good" or "enlightened" workplaces). Your career goals may be affected.
- Your confidentiality may be breached the information you provide in good faith might be inappropriately shared with other people (see the section on privacy on the flip side of this booklet, page 32).
- Despite good intentions, your employer or colleagues may treat you differently, being nervous about "making you unwell" or just feeling generally anxious about the situation.
- There are particular professions that are especially unreceptive (or even hostile) to people with lived experience of "mental illness", especially those that promote a culture of workaholism, supermen and superwomen, or that treat people with "mental illness" as "them", as different from the people who work in "this" workforce.
- Other people in your environment may respond in unhelpful ways giving unsolicited advice, for example. "Dealing" with the situation in your own way might be preferable.
- You may be a relatively private person in general, so disclosure may feel linappropriate or as though you are over-sharing (although not everyone experiences disclosure like this).

#### Some other considerations

- Think about your relationships with people you are considering disclosing to what are they like? Are you comfortable with your employer, manager/supervisor and co-workers? How do you think they would respond? What has been your experience so far with complex or difficult issues?
- Who needs to know and why? Many of us make decisions on the basis of "the need to know" or just trust our gut. For example, we may tell our colleague who sits in the cubicle opposite us, but not the entire office; or we may tell someone in the human resources department, but not our direct line manager (because maybe he's the office loudmouth).





- What are your circumstances within the organisation? Do your work skills or work performance make you particularly valued? Does your seniority make it easier (or more challenging) for you to "come out"? Is your position secure or casualised?
- Does your workplace have policies or established practices around reasonable accommodations, privacy, bullying, discrimination and leave? It can be worth checking out the specific context of your workplace.
- What has been your past experience of disclosing or not disclosing? This includes your experience of disclosing to people outside work people in the workplace also have the capacity for unexpected prejudices, foibles, thoughtlessness and thoughtfulness.
- Do you know of anyone else in the organisation who has disclosed a mental health issue? They might be open to talking with you about their experience perhaps there are some things you're not yet aware of.

#### What exactly are you disclosing?

When working out exactly what it is that you want to disclose, there are a few issues to consider.

First, it's important to make clear choices about how you want to frame your experiences, bearing in mind that we don't all communicate about our experiences in the same ways.

A dominant way of understanding overwhelming distress and extreme emotional states in Australia today is the "medical model". In this model, certain experiences are described as "mental illnesses" and treated as if they are primarily health problems, and thus psychiatrists and other health professionals are seen to be the "experts".

But this is not the only way of looking at our experiences: some people challenge this approach as unhelpful at best, or even harmful. Many of us have explored other explanations for our experiences – for example, describing them in terms of understandable, creative adjustments in response to trauma or invalidating environments, as spiritual experiences, as intense sensitivity to environmental stressors, as hearing voices, or through a lens of addiction.



How you understand your experiences – as well as what you want to communicate – will have an impact upon what you choose to disclose. For example, some of us choose to disclose using the medical model as shorthand (e.g. by naming a diagnosis – "I have schizophrenia") even though our own personal understanding is somewhat more complicated ("I hear voices when under stress. These voices are very distressing and debilitating, but they are also deeply meaningful to me.").

Conversely, some of us find a diagnosis useful, but choose not to share our diagnosis – for various reasons – and instead share information that is more specifically relevant to the work context ("I cannot make it in for meetings earlier than 9:30am because I take medications that make me drowsy in the morning").

It's worth thinking through what information it is necessary or useful to disclose. For example, telling your employer that you take a particular dose of a specific mood-stabilising medication may be relevant if you are filling out medical information to be used in case of an emergency. But in other contexts, it might be more useful instead to say that you would appreciate having the desk furthest from the heater because your medication raises your body temperature. This very clearly lets your employer know what kind of accommodations will be necessary, rather than leaving them to guess.

It is OK (indeed essential) to consider what reactions your disclosures might elicit before you decide whether and what to tell people. For example, you might be weighing up whether to disclose to your employer that you hear voices. If you suspect they might not respond well to that specific information, you could instead share how your experiences – or the specific strategies you use to manage your experiences – might affect your work. So, for example, you might negotiate that at times you will need to have access to earphones so you can play loud music. Or that it might be helpful to have the option of working in either a quiet room or an open space, depending on what's going on for you. Or that you find it useful to be able to go out for fresh air as needed, take some work to a coffee shop or wear one earplug.

Indicating what is helpful to you can be much more useful to an employer than just telling them your diagnosis or medication regime. You might like to check out the sample advance directives (page 20) for some examples of how other people have chosen to disclose in the workplace.

#### Beyond the medical model: "mental illnesses" or "experiences"?

When we think of an illness, we tend to think of something:

- Requiring hospital treatment
- That doctors know the most about
- That makes you dependent or weak
- That makes you broken, needing to be fixed, with a prognosis (i.e. expectations of a return to wellness, ongoing disability, or death).

When we think of an "experience", it can be something:

- Good or bad, or both
- That can be learned from
- Of value, e.g. when job-hunting, or helping others with something you have experienced
- That can be shared; that others can relate to
- Unique, or universal, or somewhere in between
- That no-one else is the expert on if they haven't had that experience.

Thinking about mental distress as an experience makes it a lot easier to recognise the positive as well as the negative aspects of it.

Source: So You Have a "mental illness"... What Now? (2011), available from www.ourcommunity.com.au/files/ OCP/MentalIIInessBook.pdf.

#### Disclosure: It's a personal thing

Many of us have explored disclosure in the workforce and have learnt a great deal from trial and error.

Some of us have been pleasantly surprised by how supportive a manager or colleague has been, and this has opened up new levels of honesty, connection or flexibility.

Unfortunately, for many of us, disclosure has led to discriminatory responses that have negatively affected our careers.

Most of us have had mixed experiences with disclosure and have tended to get clarity for ourselves as we navigate what, how, when and to whom we choose to disclose. This terrain is changing as more and more people "come out" about their experiences.

Ultimately, there's no one-size-fits-all answer to the question of whether or not to disclose your "mental illness" in the workplace. Regardless of what you decide to do, the process of thinking these issues through can be invaluable in itself.

#### **Further reading**

- Choosing Your Path. Disclosure: It's a Personal Decision, aimed at people with disabilities, is useful for people with "mental illness" considering workplace disclosure: http://pubsites.uws.edu.au/rdlo/disclosure/pdfs/disclosure.pdf.
- This Victorian Human Rights Commission FAQ sheet: www.victorianhumanrightscommission.com/www/files/Employers%20Toolkits/Disability%20and%20work%20-%20FAQs.pdf.
- Social Firms Australia has produced a comprehensive summary of the relevant issues, including how disclosure relates to discrimination, privacy and reasonable adjustments: http://socialfirms.org.au/sites/ socialfirms.org.au/files/product/SoFA Job%20Seek handbook May12 F web.pdf.

## It's the law: Your rights at work

There are many laws that offer protections for people with "mental illness" at work. These are outlined in detail in the flip side of this booklet: the laws cover bullying, discrimination, occupational health and safety and privacy.

In this booklet, we discuss the pros and cons of taking action against discrimination.

#### Taking action - the process and the hazards

If you believe that you have been discriminated against in the workplace because you have a "mental illness", some avenues you might want to consider include:

- Speaking directly to the person who you believe has discriminated against you, seeking an apology or a change in behaviour, or both;
- Speaking to your manager, telling him/her of your concerns and asking for support;
- Seeking confidential advice from your human resources department, trade union or occupational health and safety representative;
- Making a complaint through internal grievance procedures. Most large organisations have (or should have) a discrimination complaints policy and process;
- Taking formal legal action under the Disability Discrimination Act or the Equal Opportunity Act;
- Making a complaint to the Victorian Human Rights and Equal Opportunity Commission, the Australian Human Rights Commission or the Fair Work Ombudsman.

Each of these approaches has pros and cons, including the amount of time, money and energy required, and the likelihood that you'll want to stay in this particular workplace afterwards. Which action you take will depend



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on the incident at hand, the particular personalities of the people involved, what you want to see happen as a result of the action, the likelihood that this particular matter will be resolved, and the likelihood that broader, underlying issues will be addressed.

#### **Taking legal action**

If you decide to take action under anti-discrimination legislation, it is important to consider what you want to achieve by doing so. Taking action under anti-discrimination law can achieve the following sorts of outcomes:

- Changes to policy or practice;
- Reversal of discriminatory action, e.g. job reinstatement or promotion;
- An apology;
- Compensation for loss or harm that you have experienced because of the discrimination.

Taking any sort of formal action can be stressful, and complaints of disability discrimination are no exception. The legal system is adversarial, which means one side taking action against another, so conflict tends to be part of the process.

You may have to go over unpleasant events many times and in a lot of detail. It is advisable to keep a diary or journal of your treatment, including dates and times of events and witnesses (if there are any), so you have detailed records and evidence. Don't rely on your memory, because over time memories fade.

It is not easy taking such action. Discrimination can be difficult to prove. For example, it may be difficult to prove that the discriminatory behaviour is based on your "mental illness", i.e. that the two issues are causally linked.

It can be a particularly difficult and isolating experience to take action against your employer. In some cases relationships are so damaged that you are unable to return to the workplace.

Saying this is not intended to put anyone off making a complaint – it's often through complaints that we get changes in the workplace – but it is important to be realistic about the situation.

You may be worried that you will be harassed or victimised if you make a complaint, and this is a very real concern. However, under federal and Victorian law it is specifically unlawful to victimise a person because they have taken action under anti-discrimination law (this doesn't mean that it doesn't happen).

#### Where to get support for a disability discrimination claim

- The Disability Discrimination Legal Service specialises in disability discrimination and offers many services and supports: www.communitylaw.org.au/clc\_ddls/cb\_pages/about\_us.php.
- So too does the Australian Centre for Disability Law: http://disabilitylaw.org.au.
- Victorian Legal Aid offers free legal advice, including on disability discrimination, by telephone, as well as in its clinics: www.legalaid.vic.gov.au/2028.htm.
- The Victorian Equal Opportunity and Human Rights Commission administers Victoria's discrimination laws: www.humanrightscommission.vic.gov.au.
- The Australian Human Rights Commission administers Commonwealth discrimination laws: www.humanrights.gov.au.
- Fair Work Australia operates an advice line: www.fairwork.gov.au.



## **Returning to work after an "incident"**

Sometimes, something happens that means we can't just go on "business as usual": perhaps we have had a particularly challenging patch – or an "episode" – and have gone into hospital or had to take significant time away from the workplace; perhaps we have burst into tears in our manager's office, had a panic attack in the middle of a meeting or became entirely convinced that the IT guy was installing spywear on our computer.

There are many ways in which our "mental illness" might suddenly "come out" at work, or become the elephant in the room. In this section, we discuss the process of returning to work after such an unexpected incident. (For foreseeable situations, see the section on advance directives, page 17.)

It can feel scary, awkward or uncertain returning to a workplace after an "incident". Colleagues might not know what to say or do (or whether to say or do anything at all). Some might resort to avoidance – for example, avoiding eye contact, avoiding talking about "it" or avoiding contact with you altogether. Others might resort to offering platitudes, euphemisms, overly chirpy smiles and glib advice. Even well-meaning colleagues may not know how to approach the situation.

Working through the following questions might help make this period easier.

#### What exactly do you want others to know or do?

It's worth having a good think (or perhaps rethink) about disclosure. Do you want people to know that your behaviour (or absence) was due to "mental illness"? Do you want to have a conversation about it? Maybe you would you prefer to fudge over it with a vague description such as, "Yeah, I was pretty sick/upset/overwhelmed but I'd rather not go into details."

You might tell different things to different people. Will you tell your boss as much detail as your closest teammates? Are there particular people you'd like to tell particular things, and do you know how you'll tell them? E.g. you could email them and see if they'll grab a coffee with you away from the office.

Unfortunately, while we might appreciate it if other people took the initiative, knew where our boundaries were and kept our confidences, experience has shown us that the people around us often struggle with these kinds of situations and it can be up to us to lead by example. This might feel disappointing, since we probably already have a lot on our plate, but on the plus side, it means that we have more influence over how things unfold.

It's important that communication and requests are especially clear in the aftermath of a workplace "incident", so that you know you are doing everything you can to maintain a safe and respectful workplace for yourself. For example, you may want to put things in writing, and if you do choose to disclose, it is worth stating explicitly who else you are happy for the information to be shared with.

#### What might you need in this period of transition?

You might not know exactly what you need (or what you can request), but it's good to consider what might make things easier for you.

Many of us feel exhausted, vulnerable and ashamed in the aftermath of an "incident". Others feel invigorated, hopeful and open. There's no "right" way to feel.

For example, you might want to check whether you can work reduced hours for the first fortnight, and make the time up later in the month. Or maybe you would like your boss to know that you don't want any such accommodations – you might thrive with your normal workload (bearing in mind you don't have to be superhuman to make up for lost time).

You might like to request an opportunity to share something about your experiences at a lunch with your team. Or perhaps something smaller would be better, like a morning tea without any fanfare whatsoever.

You might like time to think about how to re-engage with your colleagues. It's possible that working from home for a few days could give you time to think things through.



We're all different and sometimes what one person needs would be the last thing someone else would want, so think about what might work for you and your particular workplace.

See also the section on potential reasonable accommodations on the flip side of this booklet, page 33.

#### Is there anything you'd want to be different next time?

If things might go pear-shaped again, would you want anything to be different next time? It is worth focusing on moving towards what would work rather than getting stuck on what didn't go right this time, although, of course, if there have been problems such as discrimination or bullying, you might follow through on these.

Most of us don't really know what to do in such situations, so it can help to learn from experience and to think ahead. While you probably want to believe there won't be a next time, this is a good time to consider writing a workplace advance directive or moving onto 48/52, if you haven't already done so.

#### Are you prepared if someone else "comes out" to you?

Most workplaces employ several people with "mental illness" (what do they say these days – one in five?), but many of us are not "out".

Some people have found that once we are "out," other colleagues decide to disclose to us. It may or may not be a safe environment for people to come out more generally – we may have only come out because this incident forced our hand.

Even though our focus may (and probably should) be on ourselves in this period, it's worth keeping one eye out for other people who might overestimate the pros of disclosure, based on witnessing our experiences.

### **Anxiety Aunt: your questions answered**

We asked our membership to share with us their questions and concerns. We hope we have answered the majority of them throughout this booklet, but some are specifically answered here, while some others (those from the perspective of colleagues and managers) are answered on the flip side of this booklet.

We call this section "Anxiety Aunt" because:

a) talking about these issues might not cause agony, but they can certainly induce anxiety; and

b) it's often the anxieties of people without "mental illness" that get in the way of honest and open discussion.

## Question: How can I discuss with my manager any "latitude" they might be willing to give me if my mental health impairs my capacity to work?

**Anxiety Aunt:** Check out the section on reasonable accommodations (the technical term for "latitude") on the flip side of this booklet, page 33. You might want to consider writing an advance directive, or have a conversation with your manager (for which you might want to check out the section on having difficult conversations, also on the flip side, page 14).

## Question: What if I don't feel confident about disclosing my "mental illness" to my employer? I'm afraid I won't get promoted.

**Anxiety Aunt:** Unfortunately, this is a legitimate concern and you may wish to carefully weigh up the pros and cons of disclosure. Check out the section on disclosure, page 6.

#### Question: What can I do if my confidentiality has been broken?

Anxiety Aunt: You have a legally enforceable right to have the privacy of your health information (including

mental health information) protected by your employer. For more information, check out the section on privacy on the flip side of this booklet, page 32.

If it was a colleague who breached your confidentiality, privacy law might not be as useful, unfortunately. You might want to look at the sections on taking action against bullying (see the flip side of this booklet, page 28) and on taking action against discrimination (see the flip side of this booklet, page 29).

Even though a breach in confidentiality can be a horrible experience, it can force us to make considered decisions about how we choose to disclose this information in the workplace (unfortunately, in this situation it may be as damage control). You may be able to get support for this within your workplace – for example, from a manager or from the human resources department – or draw on informal support.

#### Question: What if I am unwell and have exhausted all of my sick leave?

**Anxiety Aunt:** This can be really tricky, requiring you to consider whether you can afford to miss work, or whether to pretend you are OK and try to push through.

Bear in mind that this kind of problem comes up for people in all sorts of life situations – for example, people caring for a very sick relative or a child, those experiencing bereavement, recovering from an accident or living with a chronic physical health condition.

Different workplaces have different policies, procedures or approaches, and varying degrees of clarity, flexibility and experience. It is worth checking your entitlements as expressed in your contract or industrial award, and it might be useful to have a conversation with the appropriate person (i.e. a manager or someone from human resources) – you may find that there are provisions for special or compassionate leave, leave without pay, time-in-lieu, flexible work arrangements or temporary part-time hours. Some workplaces approach this case-by-case, while others have fixed practices.

This is a time to consider disclosure – exactly what you want to say about your experience and to whom.

It's also worth planning in advance for this contingency, e.g. by implementing 48/52 or via an advance directive.

This is an example of where a healthy workplace – with clearly articulated conditions, open communication and reasonable flexibility – creates the greatest chance for this situation to be manageable. The reality, unfortunately, is that you may be faced with a situation where you are no longer able to sustain your employment.

This is very tricky, as your wellbeing may be adversely affected by unemployment. We suggest it's important to give the situation thorough consideration, rather than just letting either your work performance or your wellbeing fall apart.

### Informal ways to get support in the workforce

We may decide that we don't want to disclose our "mental illness" in the workplace, or that our workplace environment is not conducive to supporting us when we are not travelling well.

This doesn't mean that we have to go it alone, however. There are many informal supports that we can draw on, whether or not we choose to engage with more formal supports (such as an advance directive, or reasonable accommodations).

#### **Friends and family**

The value of talking to supportive friends or family should not be underestimated. Having someone we can talk to and who will listen to us can be invaluable. Simply the reality check of talking to friends can reduce our anxiety, because we sometimes see things as worse than they are or just want another perspective.

Talking about concerns often gives us greater power over them, reduces our fear and breaks down the isolation we may feel.

However, many of us feel isolated or are scared of outing ourselves or letting others know how we are



travelling, often as a result of previous bad experiences. If you feel you can't talk to friends or family, you can always call an anonymous mental health support or advice line.

Sometimes it might feel as though you are not "sick" enough to need such supports – you are able to work, after all – but sometimes drawing on these supports can help you stay afloat.

#### Choose your own "carer"

Some of us have found it useful to appoint someone in our life our "carer" – someone who can support us specifically when we are having a challenging time with our mental health.

If we have an advance directive, we might list this person in it. For example, this might be the person we choose to be contacted in the event that we are unwell at work and unable to drive ourselves home.

Even if there is no formal arrangement, knowing that there's someone we know who's happy to step up when we need them may give us peace of mind. Making a choice about who would be the best person can also avoid the situation where someone who isn't the most helpful person (or who is overly "helpful") becomes involved.

#### Search the web

If you have the opportunity, search the web – there is an abundance of information, support and advice out there. You will also find online interest groups. These can be useful if you find it hard to meet people in the real world, or want to meet people with similar experiences anonymously.

The internet can be a safe place to realise that you are not alone with your illness, and you are not strange. They say that one in five people will experience mental illness at some time in their life. It just happens to be you at the moment.

#### Find a supportive doctor

Finding a general practitioner (GP) who you feel comfortable with and who understands mental health issues in a way that works for you is very important but can be a challenge. What works for one person does not necessarily work for another.

Don't be afraid of shopping around until you find the right GP for you. After all, we wouldn't buy the first car we saw. A good GP can be invaluable for things like providing evidence of the impact of "mental illness".

#### Educate yourself about your "symptoms", triggers, etc.

This isn't bad advice, so long as you can do it on your own terms. It can be useful to read about or listen to how other people understand their own experiences, as this can give us ideas of new ways of understanding ourselves – either because we relate or because we don't – and it can help expand and clarify our own position.

You might want to consider looking into WRAP (Wellness and Recovery Action Plan) – this is a tool you can use to better understand yourself. For more information, see page 17.

The better we know ourselves, the more effective we can be at getting ourselves into a safe place when things go wrong. And the more prepared we are, the better off we'll be.

## 48/52: Creating space for our lives

The term "48/52" refers to a flexible work arrangement whereby you adopt a 48-week working year (rather than 52 weeks), with the 48 weeks' worth of pay stretched over 52 weeks. This means your weekly income is slightly reduced, but in exchange you get a steady pay cheque as well as an extra four weeks of paid leave to take as needed.

48/52 was originally designed to cater for employees with young families, as part of an increased community and government emphasis on work–life balance. It's also useful for people with chronic illness and fluctuating disabilities, enabling them to get back into or stay in the workforce.

48/52 provides a way to avoid periods of unpaid leave, which can leave you suddenly short of money. It's also useful as a prevention mechanism – you can plan "mental health days" or regular leave to keep yourself running at an optimum level.

We believe that flexible work arrangements for people with "mental illness" can model flexible work arrangements for other people in the workplace. 48/52 can be a great option for anyone seeking a better work–life balance for whatever reason (e.g. caring responsibilities, preventing stress, juggling multiple interests beyond work, extra time with children).

#### What are the pros?

48/52 is a great way to increase flexibility in our workplaces. It means that we are more able to take time off when we need it, while also fulfilling the requirements of the job.

Some people (and not just those of us with "mental illness") just need a bit of mental health time up our sleeves. It can mean all the difference between being able to do the job and not. Without such flexibility, we might end up pushing ourselves to superhuman lengths just to stay afloat when we're not travelling so well.

We might believe that we're letting the team down (or we might actually be letting the team down), but we don't want to use up all our annual leave for preventative mental health days. Some of us have gone into work when we are not really up to it, simply because we've used up all our leave.

It can be incredibly stressful – and counterproductive to our longer term wellbeing – to push ourselves to keep it together and "keep up appearances" under such circumstances.

In some cases it might even lead to us "falling apart" publicly at work, which can be extremely distressing for everyone.

Some of us have also found that when we only have four weeks of annual leave, much of this gets used up for mental health related life-maintenance. 48/52 gives us the possibility of having an actual holiday.

#### What are the cons?

Of course, the most obvious drawback to 48/52 is that our annual income is reduced (by one-thirteenth).

Lack of money can itself contribute to stress and emotional distress. For some people, not being able to make ends meet may well counteract any positive effects of the increased leave.

There are logistical drawbacks too. Some workplaces, though certainly not all, require a list of dates when you apply for 48/52. As it is difficult to predict when you might get "sick", in these cases regular leave might best be used as a planned prevention strategy.

It's also important to note that, unless individually negotiated with your employer, all eight weeks of leave (four weeks of normal entitlement plus four weeks of additional leave) ordinarily must be taken within a 12-month period; you can't save it up.

Finally, taking extra leave can lead to prejudice or tensions with your colleagues. If colleagues don't know about the arrangement, you might find yourself tempted to fudge, or they may assume that you are just slacking off.

Especially in small teams, colleagues might resent being left to carry the can, and this can lead to ill-will and tensions (many people working part-time for whatever reason have reported similar tensions at work).

Conversely, if colleagues do know about the arrangements, they might misinterpret preventative leave as a sign that you're getting unwell, and this can lead to gossip or doubt about your capabilities.

Where possible, it's great to have open conversations about how you are choosing to use 48/52 to proactively maintain your wellbeing, while also fulfilling your obligations.



### How do I apply?

If you're interested in exploring the possibility of a 48/52 arrangement at your workplace, talk to your manager or the human resources department (if you have one). You might not necessarily choose to disclose that your reasons are related to "mental illness" (see the section on disclosure, page 6).

There is no legal obligation for an employer to offer 48/52, but many are open to such flexibility, and even if they are at first uncertain, you might be able to negotiate it as a reasonable accommodation.

Whether 48/52 is granted may depend on the organisational culture and whether your workplace can manage with this arrangement in place.

In a smaller organisation, your application is likely go through your immediate supervisor. In a large organisation, applications will most likely be processed by the human resources department.

## Workplace advance directives

An advance directive (sometimes called an "advance Statement") is a document that provides guidance for other people in the event that our "mental illness" affects our working life. It includes things like our preferences, what we would like other people to do in the case of an emergency, and what has been helpful or unhelpful for us in the past.

You should prepare an advance directive while you are travelling well, because it may be more difficult for everyone involved to communicate effectively in the midst of a crisis.

There are many different kinds of advance directives but a workplace advance directive is specifically tailored for the workplace.

While they are very effective communication tools, advance directives have no legal authority in Victoria (although this may be changing). That doesn't mean they're not useful. In fact, it can be incredibly useful to write an advance directive – even if it is never needed – as an exercise in thinking about and communicating what you would like from other people.

We suggest that healthy workplaces might consider advance directives for all workers, not just those who have a "mental illness". In fact, it can be discriminatory and stigmatising to suggest that only workers with a "mental illness" need to consider an advance directive. After all, we all have our own quirks and triggers.

Some workplaces that employ a significant number of people with a lived experience of "mental illness" encourage all employees (even those without a history of mental illness) to engage in a similar process.

In this booklet, we have focused on advance directives because they are simple and effective, and because they are fundamentally owned by the person with a "mental illness", which we think is crucial for their effectiveness. Some other tools that have similar benefits to advance directives include:

• Wellness Recovery Action Plan WRAP was developed by people with lived experience of mental illness, and WRAP courses are facilitated by people with lived experience. WRAP is a set of tools that people can use to proactively manage their own recovery – an advance directive is just one of these tools. Others focus on recognising triggers, enhancing self-care and drawing on available supports. WRAP is especially useful for people who experience recurrent episodes of "mental illness".

For more information, see www.mentalhealthrecovery.com.

• **Proactive interviewing** The kind of information that is useful for an advance directive may also be discussed in an interview situation. For example, questions could include: "What kinds of workplace arrangements would be most beneficial for your mental wellbeing?" or "If you were not travelling well at work, what you would hope others in the workplace would do?" Ideally, a proactive interview is a two-way process, whereby employees are also able to find out more and negotiate possibilities in the workplace. Again, we believe that such practices could become standard for all workers in a healthy, flexible workplace.





#### Types of advance directive

There are two different forms of advance directive: one is "instructional", detailing wishes, preferences and guidance for how people can most usefully respond. The other involves nominating a support person, and giving this person authority to communicate on your behalf (similar to appointing a medical power of attorney).

It's also possible to create a hybrid, where you set out some things in writing, but also nominate a person to be your support if you are struggling to communicate effectively.

If you do nominate a person, it may be useful to consider at what point you take back your authority, especially if this person is a colleague or manager.

#### **Content of an advance directive**

Following are some of the things you might consider including in your workplace advance directive:

- Information about how your "mental illness" may affect your work
- Suggestions for reasonable accommodations
- Information and guidance about what kinds of observable signs or behaviours might alert other people to the fact that you are not travelling so well. You may specify that you would prefer people let you take the initiative with this, or, alternatively, that there are certain signs that other people might notice before you do
- Information about medications you take, or about the effect of medications (including adverse effects)
- Contact information for anyone you want informed of the situation (e.g. a partner, a particular GP, a friend who is an appointed "carer"), or guidance on who you would not want contacted



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- Things that have been helpful or hindering in the past
- Preferences, values, or anything else that may be relevant.

While it's often easier to identify what *doesn't* work, it's much more helpful for everyone if you can identify what *does* work. This will be different for different people.

It also helps to think about what kinds of preventative measures might be appropriate (e.g. starting and finishing later, working from home once a week).

Ideally, the document should include a date, so it is easier to update. Signing it and having it witnessed may also add to its credibility.

#### Things to consider before distributing an advance directive

Consider whether your workplace is a safe place to be "out" (i.e. consider disclosure issues), and who might be the best people to share your advance directive with. There's not much point sharing it only with someone who's rarely present or who has no authority in a crisis.

These issues overlap – consider carefully who it's *safe* and *useful* to share a workplace advance directive with. Usually, it is appropriate to share your workplace advance directive on a "need to know" basis, i.e. to share it only with key people who are well-positioned and will ensure your stated preferences are respected.

Also consider the process of updating your advance directive – there's not much point having one if it's outdated when it's needed. You might update it annually, or when your circumstances change (e.g. when you change GP).

#### Benefits of having an advance directive

By providing an advance directive, we offer guidance on what is likely to be helpful for *us*. This information is often gratefully received by others in the workplace.

In the absence of a workplace advance directive, it's possible that managers or colleagues will simply not know what to do or will react unhelpfully – perhaps they worry about doing the wrong thing, or they assume something will be helpful when we *know* it's not helpful for us. We all have such different reactions, temperaments and preferences: providing an advance directive takes out a lot of the guesswork.

The process of creating an advance directive can also be incredibly useful for us, as a way to think through thoroughly the potential impact of our "mental illness" on our workplace, and what responses from others might be helpful and reasonable. advance directives are a proactive tool we can use to guide others, drawing on our own self-knowledge (when we are travelling well).

The document can be educative in more symbolic ways too, including sending a powerful message about stigma, shame, and self-knowledge. We are making a statement that "mental illness" need not be taboo – it can be talked about, and it is neither shameful nor "too hard".

We are also making a statement that we can be trusted to know what we need at times of distress, and that we trust other people in the workplace to be able to respond appropriately.

Moreover, a culture of advance directives suggests that the workplace itself is healthy and robust enough to have these kinds of conversations, and one in which we feel safe enough to be both "out" and respected.

Other benefits of advance directives include:

- Aiding in *preventing* or containing crises, by addressing issues proactively and effectively, rather than reactively and ineffectively;
- Improved communication;
- Greater confidence for everyone involved;
- An opportunity for discussion in a non-crisis context if further elaboration or negotiation is needed, or if there is a difference of opinion over what accommodations are reasonable.

#### Disadvantages of having a workplace advance directive

It's not always safe or useful to be "out" at work, so it's important that we think through the consequences carefully before we commit to providing something in writing for our workplace about our "mental illness". On the other hand, an advance directive is an act of communication, respect and trust. We need to use it respectfully, not making unreasonable demands (e.g. coming into work late every day without making up the time), or using it so often that our workplace grows weary of our demands.

Here are some final things to consider:

- How will my privacy be protected? How will the advance directive be stored? Who will have access to it? What if personnel change? The current manager might be "very sensitive", but this doesn't guarantee that their successor will be too.
- What is the culture of the workplace? Is speaking freely about personal concerns part of the culture of the organisation you work in? Or will providing an advance directive seem inappropriate and draw unwanted attention to yourself?
- **Too much information?** There is a danger of writing too much in a workplace advance directive and giving away more private information than is necessary. Remember, once it has been documented and dispersed we can't control where it goes.
- Will my career suffer? Could you lose opportunities such as promotion, contract extension or more challenging work by declaring your hand preemptively? Those of us who have little status in our workplace, are employed casually or are on contract might wisely be extra cautious.

## Sample workplace advance directives

[EXAMPLE I]

#### CARA DELANEY – ADVANCE DIRECTIVE 2014 SUNNYVALE COUNCIL (SC) CONFIDENTIAL

First written July 2006, updated 2007, 2009 and January 2014.

#### Introduction

This is a statement to enable those in positions of authority at Sunnyvale Council to understand my mental illnesses, how those illnesses affect the way I work, and what will help if I "get sick" / "freak out" / "go brain crazy" at work – which is very unlikely but possible.

I manage my mental illness successfully 90% of the time. It is that other 10% of time that needs thinking about.

#### **Everyday** issues

- Because I am on an extremely high dose of anti-psychotic medication it is difficult to get up in the morning so I generally start work late and finish late. I also sometimes make up extra time on weekends, if this is needed. I record my times on my fortnightly timesheet.
- I can make early appointments if necessary, but this requires me to take my sleep-inducing medication at about 7pm the night before, which means I forgo having any downtime at home. As downtime is one of my main methods of self-care, I try not to do morning meetings unless absolutely necessary.



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#### What to do

Most of the time there will be nothing for Sunnyvale Council staff to do. I'm now pretty confident and competent about looking after myself.

These are things Sunnyvale Council has done that have been very useful in helping me maintain my mental health:

- I. Flexible hours are essential;
- 2. Statistical analysis stresses me enormously, so Colin's help with this part of my work is greatly appreciated;
- 3. Capacity to go and see my psychiatrist during a working day on a regular basis;
- 4. Acknowledgement of my contribution. There's nothing like praise to stave off a few voices;
- 5. 48/52 has been a great help;
- 6. Knowing my colleagues are supported by Sunnyvale Council to fill the gaps if I have to miss work unexpectedly.

#### Instructions in case of a crisis

A time may come when too much stuff just happens at the same time and I might need some action taken on my behalf by Sunnyvale Council. If such a case occurs:

- I. Please get me away from others, both so I don't scare anyone, and so I don't have the extra pressure of any sort of scene in public.
- 2. Someone will need to stay with me until a call is made about whether I need a taxi or can drive safely. I'll usually be fine in a taxi on my own.
- **3.** Ring Kate Groves (my primary carer). She is the manager at Treedale Retirement Home and we have negotiated that she can be on call for me: (w) xxxx xxxx; (mob) xxxx xxxx.
- 4. If you can't get on to Kate, you can ring my psychiatrist, Carolyn Faffy, on xxxx xxx Another option is my sister, Alice Delaney, (mob) xxxx xxx (Please note that Kate is always my preference.)
- 5. If you can't get on to any of those listed above, ring Dad (Tom Delaney) because he is more likely to be home and can contact others. His number is xxxx xxxx.
- 6. Last resort: If things are really off the planet, you can ring my Crisis Assessment and Treatment (CAT) team triage on xxxx xxx xxx. The CAT team will tend to respond to the experiences (symptoms) of bi-polar. They will tend not respond as well to the experiences (symptoms) of complex post-traumatic stress (details follow).

#### Diagnosis

I have two diagnoses which affect me in different ways:

- Bipolar affective disorder; and
- Complex post-traumatic stress disorder (C-PTSD).

#### Bipolar affective disorder

Mostly everything is under complete control but the following things can happen:

• Feeling totally dreadful, lethargic, no concentration, falling asleep and hiding in the toilet are all issues for me if I am **clinically depressed**. It's really hard to be at work sometimes when I am really deeply depressed but other times it's fine. I'm now finely attuned to my own needs. I try lots of tricks: going for a walk, writing a limerick, doing something very mundane, going to a cafe to work there...It has the potential to interrupt



but usually not knock me for a six. I know I can push through depression and keep working even though it is hard. If I am actively suicidal I make the call not to come into the workplace so Sunnyvale Council staff won't need to deal with this. I am very responsible about this even when my leave is precarious.

• Mania is one of those things that I am less likely to recognise and I often dispute my psychiatrist's take on me being manic. Because I don't recognise it, it is probably more likely to be seen at work. It's a rare occurrence nonetheless. I'll be loud, racy, talking too much, again pretty inefficient for a while. If I catch it I try to not be at work and so far I don't think I have ever been at Sunnyvale Council when manic, but others might have a different impression. It's a sly beast. I give Sunnyvale Council staff permission to deal with it through the names provided in this document if I am noticeably responding in too strange a way.

#### Complex post-traumatic stress disorder (C-PTSD)

- **Dissociation** is associated with Complex Post Traumatic Stress Disorder. For me it means that under stress my brain simply removes me involuntarily from the cause of the distress. It is a consequence of childhood trauma. This unfortunately means that I can't deal with angst and confrontation easily without my brain just switching off. It's usually best for me, if I can, to walk away from the situation. People who know me well know that I can't take anything in when I am being held in a dissociative state.
- Flashbacks are also associated with C-PTSD. I have visual and aural flashbacks to horrible life experiences. They are repetitive. Lots of things can bring on flashbacks – feeling unfairly blamed (from the perspective of a very immature me who gets hurt too easily), being under high amounts of stress, feeling I've done a bad job (regardless of the reality), and so on. Flashbacks are unpleasant and sometimes express themselves with me losing eye contact with people, twitching, staring at my right wrist and needing to leave the room. I can generally get these to wane by stopping whatever I'm doing and going for a walk, taking a trip to a coffee shop or talking with someone.
- Hearing "voices" is also associated with C-PTSD. They are horrible but manageable. They come in two different forms:
  - I. "Command voices" tell me I have to do things e.g. they tell me I have to cut my arms, infect a sore, bash myself up, walk through a glass window and so on. They never command me to hurt anyone else. Everyone is safe! I'm usually on top of these and can remove myself from the workplace in good time.
  - 2. The second set of "voices" are a dreadful rhythm of known sayings which often elicit responses from me like "If you touch me I'm going to kill you"; "I hate you so fuck off"; "If you come anywhere near me I'm going to kill you"; "Fuck off you bitch". I've been living with these "voices" for many years and 90% of the time I have them under control. If I am experiencing them, I'll disappear somewhere so I don't scare or worry anyone else and I am able to do this.

## Robbie Marley's advance directive: Dept of Music

#### Accommodations for Robbie to maintain wellbeing

- I need a *lot* of sleep! This means I tend to start late and finish late.
- Sometimes I need to take time out during the day by spending time elsewhere, e.g. in a cafe, or leaving for a walk, or leaving early to finish my work at home. Sometimes I may prefer to work from home to take care of my mental health. I tend to be self-aware enough to know when I need to do this.

#### In the event of Robbie being unwell in the workplace

- I may leave work if I feel like I am starting to go downhill (or if I've forgotten to take my medication). If you are unsure about my safety to drive (if I am driving), or to catch public transport, please ask me. A taxi voucher would be appreciated in such circumstances (I often won't have enough money for this otherwise).
- The most likely version of "unwell" for me (that might present in the workplace) is being very emotionally unsettled under stress. It may be visible in my face and overall body language, which become very tense. In such circumstances, I tend to shut down, cut off emotionally, become highly sensitive and have difficulty communicating. My thinking becomes cloudy and it takes me a long time to process information or make decisions. My communication may be confusing to others. If you are patient, I am generally able to communicate clearly eventually. Please do try to communicate, with patience and honesty. If you lose your patience, or if I suspect you are being dishonest, it will escalate the situation.
- If you are acutely concerned for my wellbeing, please contact people listed as my emergency contacts (below). Please DO NOT call the Crisis Assessment and Treatment Team, or any other mental health service, unless none of these contacts is available and you truly feel you have no alternative. My experiences in the past have been very negative and tend to make things much worse for me.

#### In the event of Robbie being unwell outside the workplace

- If I am acutely unwell, I may take up to four days to return phone calls or emails. But otherwise, it is very unlikely to affect my work. I may need to take sick leave, or rearrange my working schedule to take time out.
- Feel free to tell others I am unwell. Be vague about the details, but please don't fabricate excuses.

#### **Emergency contacts**

- I. If a psych-trained person is considered desirable, please contact (in order of preference):
  - Paul Attention (Psychologist, Carnegie): xxxx xxx xxx
  - Dr Suresh Mahar (my GP, Doctors of Carnegie): xxxx xxx xxx
  - Dr Linda Quickly (psychiatrist, Southpark Private Hospital, Dandenong): xxxx xxxx
- 2. If psych training is unnecessary: Lisa Simpson (sister): xxxx xxx or Colleen Matesy (close friend): xxxx xx.

#### **Relevant medical information**

• I take 800mg of Lapsical and 15mg of Deliopac daily, and I am allergic to codeine.

