

‘She was begging for help’

Kerry Nicholas did everything she could to help her daughter. So why is it so hard to get proper treatment for people like Sophie?

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STORY: KATE LEGGE | PHOTOGRAPHY: JULIAN KINGMA

Sophie Nicholas gazes from a photograph stuck to the fridge door in the kitchen of her family’s Melbourne home, her intense eyes crinkled with laughter in a moment of exhilaration, her long brown hair swept back from her face on a windy day when the troubles that cursed this 26-year-old hid from sight. Pale pink and cream rose petals dry on wire trays atop the wooden table near a towering pile of condolence cards as her mother Kerry leafs through a large file tracing Sophie’s chaotic shuffle between rehabilitation and emergency departments as she wrestled alcoholism and borderline personality disorder (BPD).

The paper trail chronicling multiple admissions, discharges, psychology reports, police statements and health insurance claims during the past two years obscures a darker tale of heartbreaking failure to treat a mental illness that is complex, challenging and misunderstood. Kerry tries to

make sense of the tipping points: Sophie's desperate voice in a 3am phone call when she'd been discharged yet again from emergency with nowhere to go; the sight of her dishevelment after losing wallet, phone and possessions while intoxicated and homeless; the three days she went missing with enough medication to overdose before she was found camped in the back yard of an unoccupied house next door.

Wry humour intervenes sometimes: recognising paramedics by their first names because they'd been called so often or realising her daughter's cunning wiles in an already "dry" house had stripped the pantry of everything with a trace of alcohol, even vanilla essence and bitters. Tenderness, too, as she recalls her daughter's compassion for other broken souls. When a residential rehab place opened suddenly in late August, Sophie fretted at leaving behind an older woman, an alcoholic who had stolen her phone in the rooming house they shared. The soaring hope of possibility and a fresh start drew urgent promises. As she scrambled to get clean she'd beg: "I need help Mum. I can't bear it anymore." After each relapse came the rasping soundtrack of failure. "She said to me a couple of weeks ago, 'When I wake up in the morning I don't want to be here', "

Kerry recalls.



Sophie Nicholas.

Sophie couldn't stay sober for long enough to get help with the underlying cause of her addiction. Mental health services didn't want her while she was drinking and rehabilitation programs did not have the specialist care to tackle the illness that craved relief. This is the double whammy driving urgent calls for dual treatment of addictions and disorders such as BPD.

Sophie didn't stand a chance. At a service last month to celebrate her life, friends and family described her rare intelligence (she spoke Danish and Japanese) and her creativity as a photographer. Two older siblings told how as a child Sophie would tremble with excitement as if she couldn't contain the soaring uplift of anticipation. "I'm fired by loveliness," she'd declared aged seven, breathing scented flowers in the garden of her bayside home. But an inability to regulate intense emotions is a defining trait of her disorder, which went untreated as she bounced between emergency and rehab.

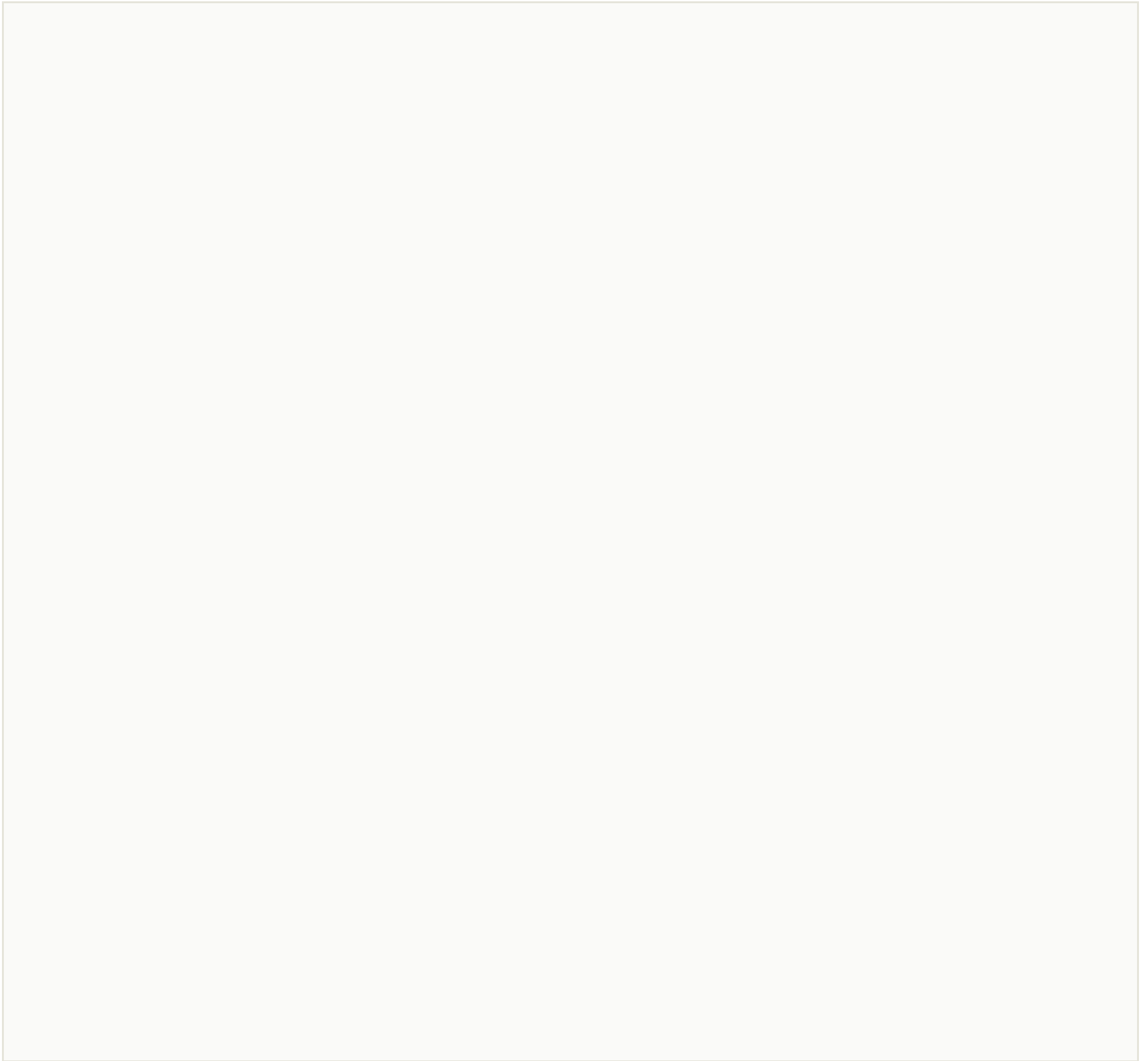
This is the uncomfortable fact Kerry Nicholas wants to change even while her grief is as fresh as the roses delivered to her door after Sophie's death. When it was her turn to speak about her daughter to the crowd that gathered on an overcast Melbourne day, she started at the beginning, with a baby so beautiful and engaging it was difficult to get from one end of the shopping centre to the other because so many people were drawn to stop and smile. She talked of her spirit, her dry wit, and her pluck. So much in this short life was good and full of promise. She urged mourners to look behind the acronym BPD and learn more about an illness that affects an estimated 1-4 per cent of the population (at least 240,000 people). She asked those gathered to give money when they walk by the homeless because Sophie had benefited from spare change while sleeping rough; she encouraged acts of kindness just as strangers had shepherded her daughter into ambulances on the worst days.

Last December, before she made her first attempt at suicide, Sophie scratched an eloquent note to her mother on a framed canvas expressing eternal love and a desperate howl of pain. "I'm not leaving you," she wrote. "I'm leaving me."

Comedian Felicity Ward, who experiences anxiety, kicked off National Mental Health Week in mid October with an article entitled "Five Things You Don't Know About Anxiety, Depression and Mental Illness" including the admission: "We smoke and drink more, take more drugs, eat worse and exercise less which is a sneaky way of saying WE'RE HEAPS MORE FUN."

Borderline Personality Disorder secured its own awareness week two years ago – scheduled as a curtain-raiser for mental health week – but in a calendar already crowded with causes, few would have known. Celebrity spokespeople are thin on the ground. Specialists who encounter it daily describe BPD as the Cinderella of mental illness to underscore its place at the bottom of a pecking order in a health system more comfortable curing

physical ailments than troublesome minds.



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It's not known exactly how a person develops BPD, although there is evidence of inherited traits that can be exacerbated by adversities such as childhood trauma. We know sufferers experience terrifying fear of abandonment, unstable relationships, uncertain identity, impulsiveness, risk-taking, self-harm through mutilation, starvation or addictions, suicidal thoughts, intense anger, paranoia and an inability to regulate emotions. We know these behaviours intensify from puberty through early adulthood, fuelling self-medication with illicit drugs or alcohol to numb the pain. We know that people with BPD face a high risk of suicide. New figures released by SANE estimate this group is 45 per cent more likely to die

than those with depression, bipolar or schizophrenia, and this threat rises with substance abuse.

Serious research into the disorder began more than 30 years ago in the US but knowledge of the psychotherapies that bring relief is not embedded in front-line services around Australia. The few clinicians skilled in diagnosis and treatment blame this ignorance on old-fashioned attitudes and a stubborn perception that these patients do not appear mentally unwell. They might be cutting themselves or overdosing but they do not exhibit psychotic behaviours common to schizophrenia or bipolar. When they present at emergency departments they are often dismissed as manipulative attention-seekers. There is no pharmacological magic pill but if specialists are properly trained, if therapy is provided and if there is the will and wherewithal to end a historical demarcation between health services so that the demons of mental illness and addiction can be addressed in tandem, patients can recover.

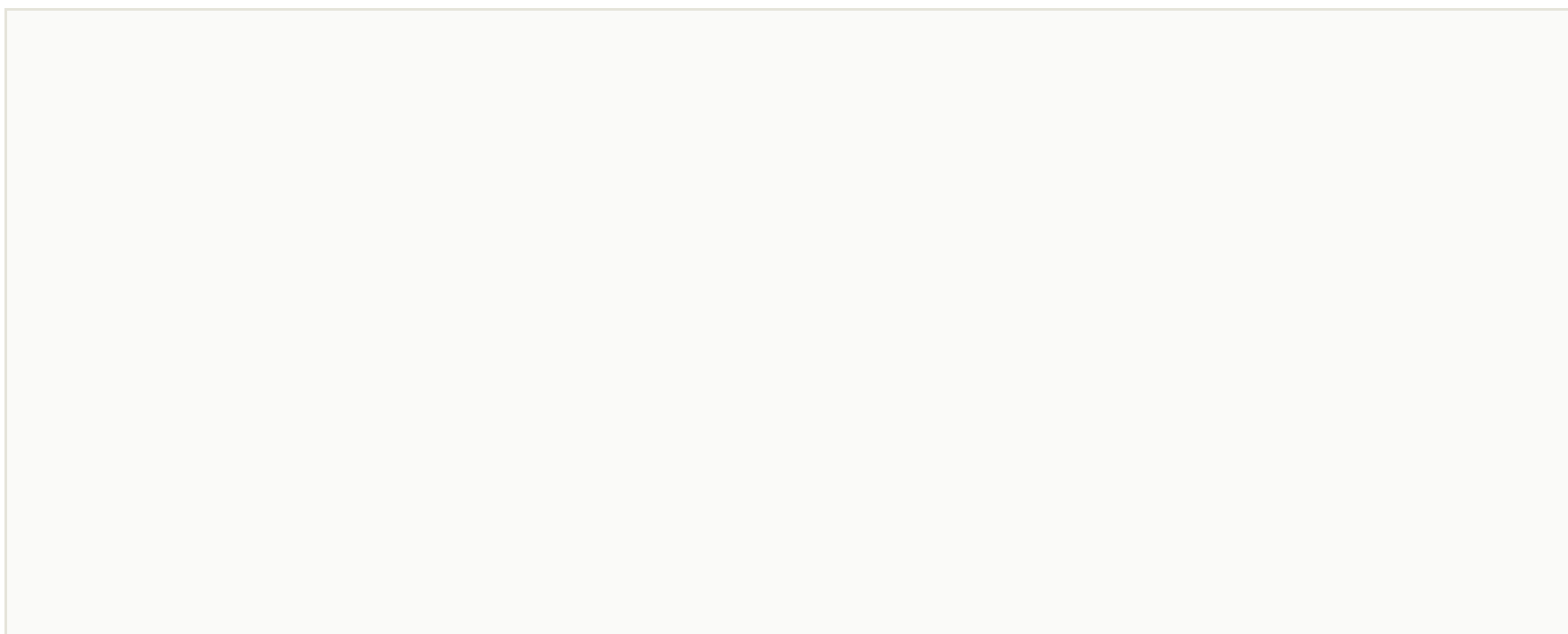
Like almost every psychiatrist in this field, Sathya Rao, who runs Victoria's Spectrum, the only state-based BPD service, was taught the diagnosis but given no tools for treatment. "We were told there is nothing you can do, that it is a hopeless condition and we should just leave patients alone." Arriving here from India 20 years ago, he was posted to a hospital in rural Victoria where his very first patient had severe BPD. "I didn't have a clue what to do and she was suffering so badly. We admitted her numerous times before she was given psychotherapy and with the right treatment she got well. I could see the huge difference this care made for someone with this condition."

Another Victorian psychiatrist, Professor Andrew Chanen, whose research in this fledgling field has attracted international attention, says his interest grew from the same black hole. "When I was training I was taught this is a group that nobody understands – 'they are indestructible; they turn up at emergency departments then move on' – but I soon realised through

talking to friends and colleagues that these same patients were churning from one emergency department to another and by the end of my training the most notorious patients were dead. It was a real epiphany to me that we had to do better.”

Two decades later, patients continue to be discharged without help because our approach is chaotic and haphazard. “Every single Australian needs to know of this disaster,” says Rao. “People are dying because of suicides while up to 85 per cent of these patients self-injure, repeatedly; they live horrible lives. We just don’t have the training framework in place and there is so much stigma and discrimination. Mental health services are so overstretched and people with BPD get the worst care of all, partly because they are so challenging even for clinicians who are trained to manage them.”

Fragmented mental health services are difficult enough to navigate but for people with an illness defined by poor interpersonal skills, anger outbursts, thin emotional skins and self-destructive behaviour, the chances of securing high-quality care are slight. Clinical practice guidelines for managing this disorder were finally issued by the National Health and Medical Research Council in 2012 but have yet to trickle through acute care settings.



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“These patients are still seen in some circles as manipulative and wilful,”

Professor Chanen says. “There is not just ambivalence but hostility. We still have this legacy of old-fashioned views that regard this group as intentionally harmful because they drink heavily or cut themselves. Manipulative?” He almost shouts his frustration. “I would respond by saying this group is incapable of manipulating people. Those who are good at manipulating people are seamless. These patients are terrible manipulators. They are just trying to get relief. Their behaviours are so coarse but this is the best they can do to manage out-of-control emotions and terrible distress.”

Treatment can be hard to come by. Spectrum is limited to the most severe cases who’ve attempted suicide or self-harmed, caring for only 500 people a year. Rao receives desperate calls from families around the nation every week. “Some relocate here just to get help. I help out in other states but they are in a very bad shape. We need a Spectrum in every state. This should not be happening in Australia.”

Orygen, the National Centre of Excellence in Youth Mental Health, where Chanen is based, services Victoria’s western suburbs catchment where demand for treatment exceeds supply. He estimates there are 5000 young people in this growth corridor with unmet needs. “People move into the catchment area to get treatment,” he says. NSW has a smattering of services in Sydney as well as the Centre for Psychotherapy in Newcastle where families migrate in search of help but here, too, Dr Chris Willcox laments a lack of resources. In South Australia, psychiatrist Martha Kent describes “a scandal” with waiting lists for therapeutic BPD treatment in Adelaide lengthening to two years.

Family Connections, a program designed to educate parents in how best to manage adult children with the disorder, has a waiting list of 1000 around the country. A mother who helped spearhead this training says she rang 45 psychiatrists when her adult child was first diagnosed but none was available. She speaks with quiet desperation – life for her daughter, who

has an eating disorder, is perilously poised. “What happens to the people on waiting lists? They die.”



Beth McMullen

Those able to access good care are beacons in the blackness. Former radio producer and actress Beth McMullen, 31, is proof that intensive therapy by skilled clinicians paves a road to recovery. Now in remission, she's brave enough to talk about the disorder. “Addiction is the one thing I managed to avoid,” she acknowledges gratefully. “The times I've caused harm to myself I've been under the influence of alcohol and disinhibited. It turns up your self-loathing.” Before getting help she experienced suicidal episodes, eating disorders and periods of cutting or hitting

her head. “The pain you inflict grounds you,” she explains. “It physically brings you into your body and calms you. It's a punishment. You feel unworthy, as if this is what you deserve. I get really prickly when I hear - people say, ‘It's a cry for help’ because this feeds the stigma that we are attention-seeking and manipulative.”

Typically, McMullen was mislabelled initially with bipolar and depression but the medication she was prescribed didn't dull her symptoms. When she resigned from her job and shifted house five years ago, she became severely suicidal and wound up in emergency. “The treating registrar told me, ‘I'm not admitting you because this is for extreme cases. Go home

and wait to get treatment.’ There was a three-month wait. I could have easily fallen through the cracks. No wonder so many people suicide, because the problems just get worse.

“I always describe my diagnosis as though I was living in a dark room full of lots of crap that I kept bumping into and hurting myself. With treatment, the light went on. I felt immediate relief because I realised the magnitude of what I was dealing with.”

Her fortunes turned when she began seeing Chris Willcox, a psychologist trained in psychological therapies acknowledged as the most effective evidence-based treatments. She commenced 12 months of intensive individual and group therapy that taught her how to regulate emotions and resist the overwhelming sense of doom that derails her. Her mother completed the Family Connections course that trains parents and siblings in how to manage sufferers by validating their feelings.

Willcox experienced the same therapeutic blank stare that inspired others in this fledgling field to pioneer reform. “When I joined the mental health system there was this view that borderline patients were untreatable but I saw this differently.”

Perth-based Chelsea Ganfield, 29, is further proof that intensive therapy can transform lives. She began cutting as a teenager (“my coping mechanism”) and wound up in emergency. Like McMullen she was misdiagnosed with bipolar, depression and anxiety and given anti-psychotic medication that stabilised her mood without treating her intense

emotional upheavals. She was similarly blessed by a psychiatrist who “diagnosed me on the spot and I remember the moment where I thought, ‘You are reading my life’ ”.

Referred to psychologist Sian Jeffrey, who specialises in dialectical behavioural therapy, - Ganfield began individual and then group therapy, relying for a while on tapes made by Jeffrey to calm her when extreme distress took hold. “Cutting was something I did for release and distraction. I had no idea how to manage it differently until I was given new tools. I have so many techniques now.”



Chelsea Ganfield.

A psychology graduate who also trained at the Western Australian Academy of Performing Arts, Ganfield is keen to raise awareness of the disorder. “The biggest thing is stigma. I’ll never forget the day one of my psychology professors at Murdoch University told the class, ‘If you ever come across someone with BDP run for it, because recovery has such a low success rate.’” She no longer experiences the emotional surges that once unravelled her. “Massive pain is what I felt and massive pleasure now that I’ve stopped my behaviours. You’ve got to give people a sense of hope.”

Everyone I interview knows anecdotally of a recent suicide. Janne McMahon, who runs a consumer advocacy group for BPD, is aware of 10

deaths this past year. “These are only the ones I know of. There is crisis after crisis. How many lives do we have to lose before something happens?” She says Sophie Nicholas’s story is not unusual. “And that is the saddest thing. These young people with BPD are often highly sensitive and artistic. They seem to have one less layer of skin.”

Spectrum wants a dedicated suicide registry for BPD to determine true mortality rates as part of a national plan to retrain mental health staff and roll out specialist hubs across the country. Orygen begs for dual treatment of alcohol and drug use by our young mentally ill. Seventy five per cent of disorders develop before the age of 25 when young adults are most prone to substance abuse, one intrinsically linked to the other.

Professor Patrick McGorry, Australia’s best-known pioneer of youth mental health services, claims the mainstreaming of mental health care in the 1990s was meant to coincide with an expanding system of community-based expert multidisciplinary teams. “This has been largely abandoned,” he says, resulting in a “grim and unacceptable” landscape for complex disorders such as BPD.

“There is no place for the multitudes with these problems,” laments Maureen Beer, whose daughter Liana died in April aged 32 after battling BPD and an addiction to butane. “The rehabs are not equipped to deal with mental illness. They don’t have the skills to handle people like this. It’s too difficult. I know it’s not easy. The mental hospitals do not want patients with addictions. They treat them like druggies. And so the cycle continues with overdose, paramedics, emergency, detox, rehab, and then discharge. I always felt so helpless.”

An excerpt from the diary Maureen kept during this spiral illustrates the problem. After Liana binged on butane in February 2013, her mother brought her home on a Sunday night.

I told you I loved you and that together we could pull through this. When I

woke up on Monday morning at 8am you had gone. That night I had a call from the hospital. The doctor said you had been discharged from Caloundra Hospital. You were found later at the side of the road by a motorist who took you to Nambour Hospital. They checked you out and say that you are just fine. I told him that you are not fine, that you have tried to choke yourself using a scarf and you are trying to choke yourself using coat hangers. I pleaded with him to have you assessed by mental health... They say you are fine other than your problems with substance abuse. They called a taxi for you. You left the hospital before it arrived...



Kerry Nicholas.

Kerry Nicholas lurched through days, nights, weeks and months of similar torture. She tried to get Sophie on Spectrum's program but she was assessed as not severe enough. "For most of this year she was either in rehab or in hospital or lying in her bedroom.

Whenever she got into a detox program they'd give her leave and she'd come back drunk or smuggle alcohol in and they'd kick her out." A private psychologist who offers intensive behavioural therapy refused to take Sophie because of the drinking. Attempts to secure another rehab stint stalled. The private hospital where

she'd been three times before knocked her back, then another agreed to admit her for detox.

Her final days on Earth underscore the tragedy she faced. After she'd been

clean for three weeks her father, Andrew, who lives in Singapore, had a stroke. She relapsed and was told to leave rehab. Had she stayed sober for a week longer she'd have been guaranteed a place in a residential care facility with support to get therapy and traction for recovery.

Days later, Kerry got a call from an apartment complex where Sophie had shown up in no fit state to be given a bed. She collected her daughter and they drove to the nearest emergency department. A scuffle broke out in the car park as Sophie tried to run, alerting security; she was admitted and eventually shackled to the bed with a code grey alert requiring a guard. The crisis assessment team (CAT) was called but didn't show so Kerry left after an hour, confident her daughter was safe.

At 3.30am Sophie called, distraught, to say she'd been kicked out. Emergency staff refused to explain why. "When I finally got through to someone they said, 'We can't keep her because she broke our rules'," she recalls.

"She shouldn't have been discharged from rehab 21 days into a 28-day program. She shouldn't have been discharged by the hospital. The CAT team never came to see her. If they couldn't get her assessed she should have been walked to their psych ward 200 metres down the road."

Police are investigating the circumstances of her death. "She told me a number of times, 'I think about suicide every day, but I'd never do it to you Mum'." Her threadbare resolve couldn't grasp the handrails of hope and help to keep this promise.

For crisis support: Lifeline 13 11 14

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NEXT
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