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Background

Lived experience of eating disorders and body image concerns lies at the heart of Butterfly's work as it connects us to our origins and the communities we serve.

Butterfly was founded by Claire Middleton in 2002, a mother of two daughters who had suffered from anorexia nervosa. Claire had become acutely aware of the lack of resources available and found it very difficult to find help for her daughters. Since this time Butterfly has been regularly called upon by governments, researchers, the media and other stakeholders to provide a 'voice of lived experience'.

In 2020 Butterfly enhanced our lived experience engagement through two new formal mechanisms to help bring about change to culture, policy and practice in the prevention, treatment and support of those affected by eating disorders and body image issues. Our aim is to embed lived experience across all of our work by creating opportunities for people with a lived experience to inform our strategic direction and provide advice on projects and activities happening across the organisation. Through our renewed commitment to listening, amplifying, and advocating for lived experience voices (Priority 1.1 in our Strategic Plan) Butterfly seeks to recognise the value of lived experience as a form of knowledge and draw on it as a force for positive change.

In 2021 Butterfly launched two new mechanisms to elevate the voice of lived experience in our work and across the sector as a whole. Our strategic advisory body, the Lived Experience Community Insights Group (LECIG), and our broader online community, the Butterfly Collective, have been guiding us and contributing to the work of other mental health organisations, researchers, clinicians and government policy-makers since their respective launches in April and May 2021. Both groups have informed Butterfly's service development, campaigns, projects and more recently our advocacy priorities in relation to the eating disorder system of care.

In October 2021, Butterfly approached this growing lived experience community to undertake an exploratory exercise to develop an in-depth understanding of the experiences of people within the eating disorder system of care, either for themselves, or in support of a loved one.

Overview of the current eating disorder system of care

Treatment for eating disorders can be accessed through a range of health care settings.

These include specialised and non-specialised mental health services, such as community mental health services and admitted patient care.

People with eating disorders can present to General Practitioners, psychiatrists and paediatricians where, since November 2019, they can be assessed for the development of a Medicare-subsidised Eating Disorder Management Plan (EDMP). 64 MBS Eating Disorder Schedule items enable people with complex eating disorders to access up to 40 sessions with a mental health professional (psychologist, social worker, or occupational therapist) and up to 20 sessions with a dietician annually. A psychiatric review is required mid-plan to access the full number of sessions.

A wide variety of specialised eating disorder services and organisations can also be accessed by people needing support, including child and adolescent mental health services and specialised inpatient eating disorder services. Lived experience organisations such as Butterfly and state-based services such as Eating Disorders Victoria and Eating Disorders Queensland provide a range of treatment programs and recovery support programs, including skill development programs, peer mentoring programs and carer support groups. Butterfly's National Helpline provides free telephone advice, counselling and referral. Butterfly maintains a searchable database of health professionals and services who have been screened for experience in treating eating disorders.

Launched in November 2021, the new ANZAED Eating Disorder Credential provides a recognition of qualifications, knowledge and training for mental health and dietetic eating disorder treatment providers to ensure that minimum standards safe and effective eating disorder treatment are met. Administered by Butterfly, the federally-funded National Eating Disorder Collaboration (NEDC) synthesises research evidence, clinical expertise and lived experience in national standards and workforce initiatives to build an effective, equitable

and accessible system of care across Australia. NEDC initiatives include a Resource Hub and Eating Disorders Quality Improvement Tool (ED QI) for Primary Health Networks, and the Eating Disorder Core Skills eLearning for GPs training.

The various 'tiers' of support which form the eating disorder system of care are summarised at **Figure 1**, below:

Hospital/Residential Services

- Paediatrics/Adult
- ED unit/beds
- Medical and MH P units

Public Mental Health

- CAMHS/CYMHS
- Adult AMHS
- Paediatrics OP
- Community ED clinic
- Day Programs

Headspace Centres Private Practitioners

 Paediatricians, Dietetics, Mental Health

Community Health Services

Dietetics, GP, counselling
 GPs

Primary Health Networks

Health Pathways teams
 RACGP

Private Clinics

ED units

Emergency Departments

Private Clinics

• ED Day Programs

ED Private Clinicians

 Dietitians, Psychiatrists, Physicians, Paediatricians

Lived Experience organisations

Peer support, mentoring, information

Mental Health Nurses

 Mental Health Nurse Initiative Program

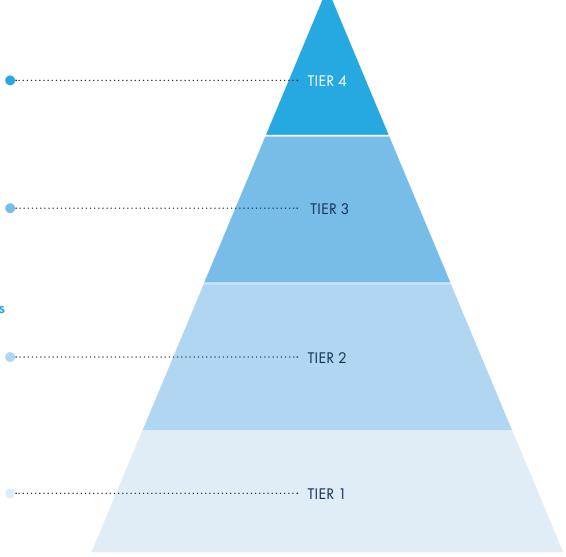
Schools

Education staff; welfare; wellbeing; SSSOs

Sports Coaches

Youth Services

University Counselling Clinics



Source: NEDC

Challenges in seeking treatment

People seeking support and care for an eating disorder face many challenges both within and outside of the current system of care.

As set out in the National Agenda for Eating Disorders 2017-2022 (Butterfly Foundation, 2017), key challenges in addressing eating disorders include: the availability of a skilled workforce; access to affordable, integrated physical and mental health care; the need for early identification; gaps in the continuum of care; and enabling sustainable recovery.

Exploring of the lived experience of someone who has navigated the system of care is fundamental to understanding the tangible impacts and real life implications of the pathway to recovery for people with an eating disorder and those who support them. In attempt to understand the stories that sit behind the system Butterfly invited the Lived Experience Community Insights Group (LECIG) to undertake a journey mapping exercise to unpack several pathways through various stages in the system of care. Barriers and enablers were uncovered at each stage in the journeys, with a reflective exercise identifying opportunities for positive change.

This exercise drew on the diverse experiences of all 14 members of Butterfly's LECIG and employed a Human Centred Design methodology to ensure lived experience was central to the process. Five journey maps were developed which provide a representation of how people with lived experience ('personas') interact with the system incorporating their feelings, attitudes and behaviours at each stage of their journey, highlighting a series of key touch points and pain points.

About the Lived Experience Community Insights Group (LECIG)

The LECIG is a 14-person strategic advisory group.

The LECIG was established to inform Butterfly's strategic direction and ground Butterfly's decision-making in the wisdom of lived experience. The role of the LECIG is to:

- Assist Butterfly to empower and amplify the voices of people around Australia who have experience of an eating disorder, disordered eating or body image issues, and those who care for someone affected.
- Provide advice on how Butterfly can develop and maintain a culture that will embed lived experience across our work streams, including incorporating lived experience perspectives across: prevention; program design, implementation, evaluation and review; and engagement.
- Assist in the development of awareness-raising, anti-stigma and policy advocacy campaigns.
- Support Butterfly to become more representative of the diversity of eating disorders, and the diversity of the Australian population, including being a 'critical friend' to help us develop services and programs which meet the needs of the whole community.
- Develop a work plan of priority actions that elevate lived experience knowledge throughout the eating disorder system of care and across the mental health sector.
- Provide a vehicle for contributing insight to new investments and reforms within the eating disorder system of care and other relevant public policy development.

Current members were appointed for a two-year term through an open, two-stage Expression of Interest process. The group is made up of people who have personal experience with a range of eating disorder and body image concerns and include the experience of carers, people from metropolitan and regional areas, people of differing ages, genders, sexualities, and cultural backgrounds. The LECIG is Co-Chaired by Butterfly's CEO Kevin Barrow and LECIG member Zoe Bush.

The journey mapping exercise

To purpose of the exercise was to define and understand the experience of people and their families/carers accessing, entering, and moving through the eating disorder system of care though:

- Exploring what a common journey through the system of care looks like
- Identifying key touch points for provision of support and treatment
- Identifying key enablers and barriers to recovery that currently exist within the system
- Exploring opportunities for improvement at critical junctions in the system of care.

Methodology

LECIG members came together in an online half-day workshop to map lived experience journeys through what was identified as the key points of interaction with the current system of care across stages within the care journey. Using personas and the mapping process, the group created several lived experience pathways through each of these stages.

Four personas were initially developed to track the experience of navigating care – Jayne, Lee, Jiro, and Jess. A fifth persona – Alex – was developed after the workshop to capture the input of a LECIG member (who was unable to attend the workshop) who has a personal experience of trying to navigate the system of care as a trans person (see **Appendix** for each persona).

Personas are fictional prototypes that represent a potential person and the scenarios they face in the context of experiencing an eating disorder. They have individual names and stories that reflect personal attributes and behavioural characteristics such as needs, motivations and attitudes. While the chosen personas don't perfectly reflect all experiences, they provide a safe space for projecting lived experience and assist in bringing the person navigating care "to life". In this way the personas provide the context required for identifying potential pain points within the system e.g., "What would happen if Lee was not supported by an adult to seek help?".

In the workshop, members broke into four small groups to work through each persona's feelings, thoughts and behaviours, with content added to a draft journey map. Maps were then shared with the full group.

Developing solutions and prioritising recommended actions

After working through the journey maps in detail the key barriers to care were collated and LECIG members were asked to consider potential solutions to addressing them. Members were encouraged to think of ideas that could be implemented both within and outside of the current system. After further consultation with the LECIG members post-workshop, these ideas were translated into a series of lived experience advocacy priorities which were then grouped under four broad themes: improved access to services; help-seeking information; awareness, challenging stereotypes/harmful social norms and reducing stigma; and training and education.

Further prioritisation was undertaken via a second stage of consultation with Butterfly's broader, 300-person online lived experience community, the Butterfly Collective. Members of the Butterfly Collective were provided with the context of the exercise, asked to reflect on their own experiences, and vote on the top two barriers to quality care and their top five advocacy priorities.

Findings

Barriers to care

The journey maps (on pp. 9-28) reflect various paths through the system of care. Differences encompassed different types of eating disorders and how they may present, whether their experience was as a carer or an individual seeking treatment, cultural background, level of support networks, age, gender, sexuality and geographic location. Several barriers were consistently identified throughout the different points in the journeys, from initial help seeking, to accessing treatment, leaving treatment, and recovery. The following barriers were perceived as common hurdles across all of the personas:

- Stigmatising attitudes about who gets eating disorders and what an eating disorder 'looks like' and what an eating disorder is/isn't
- Difficulty finding information at all stages, from identifying if there is a

- problem, to initially reaching out for help to suitable treatment, to treatment and post-recovery support and relapse
- GPs and other health professionals being ill-informed about eating disorders (e.g., invalidating individual (and loved ones') experience, stigmatising attitudes, lack of understanding about eating disorders)
- Conflicting health advice and social norms (e.g., diet culture, fitspo
 movement, clean eating movement, social and economic rewards for being
 a smaller size)
- Use of current diagnostic measures to meet 'sick' status; and receive help/treatment (e.g., not being perceived as 'sick enough' due to BMI measurement)
- Inability to access services (e.g., waitlists, location, financial situation, suitability of services such being as culturally inappropriate or unsafe for trans and gender diverse people, not eating disorder-specific)
- Limited support available post-treatment.

Top two barriers to care

- Stigmatising attitudes about who gets eating disorders and what an eating disorder 'looks like' and what an eating disorder is/isn't
- Conflicting health advice and social norms (e.g., diet culture, fitspo movement, clean eating movement, social and economic rewards for being a smaller size)

Lived experience advocacy priorities

In addition to identifying the main barriers, LECIG members generated several ideas to address the systemic issues addressed during the journey mapping process. Some of the solutions require system-level and sociocultural change, whereas others require an investment in education, training and health promotion. The ideas borne out of the process have been broken into four broad categories: improved access to services; help-seeking information; awareness, challenging stereotypes/harmful social norms and reducing stigma; and training and education. Butterfly Collective members were then asked to vote for their top five priorities from across all of the categories as listed below:

Improved access to services

- A stepped care approach to treatment and support ensuring people get what they need at the right time
- A care navigator role to help individuals and families navigate the current system of care (e.g., who to speak to, options available, what to plan for)
- Support to people who are on waitlists for treatment
- Information for individuals and families on their rights as health care consumers (e.g., how to make complaints, expectations of care) and information about how to advocate for treatment and support
- More treatment options in regional and remote areas
- Safe and fit-for-purpose treatment for people in the LGBTIQA+ community
- Post-treatment support services and programs
- Enforceable remedies in response to discriminatory practices

Help-seeking information

- A clear picture of what the journey to recovery can look like with information about support options at each point (e.g., identifying if there is a problem, treatment, post-treatment)
- Resources to support family, friends and carers with how to have conversations about eating disorders with loved ones they are concerned about
- One trusted source of truth for eating disorder information and support
- Highlighting that (in the current system) it is normal for people with an eating disorder to think they are 'not sick enough' and encourage early help-seeking

Awareness, challenging stereotypes, and harmful social norms, and reducing stigma

- More diverse representation of who is affected by eating disorders and what an eating disorder is in the media/social media
- A national campaign to raise awareness about an eating disorder being a mental illness, including myth-busting
- A national advertising campaign about diet culture and its impacts

- Harnessing influencers to raise awareness about impact of diet culture and other social norms which contribute to poor body image
- Increased accountability in gyms/fitness centres/health programs (e.g., require them to provide information about health and the dangers of overexercise rather than weight loss)
- More culturally specific information and support be made accessible to different cultural and language groups across Australia

Training and education

- Education in schools about HAES (Health at Every Size) principles and the dangers of over-exercise, dieting and restrictive eating
- Community education programs about how to navigate everyday conversations about healthy eating, weight, and diet
- Education for GPs and other health professionals about the impact of stigmatising language and behaviours (e.g., developing an eating disorder-specific language guide)
- Professional eating disorder-specific training for all health professionals who may come in to contact with someone with an eating disorder
- Add/improve the breadth of eating disorder content in current curriculum for mental health qualifications (e.g., psychology, counselling, Certificate 4 in Mental Health)

Top six advocacy priorities

- Professional eating disorder-specific training for all health professionals who may come in to contact with someone with an eating disorder
- Education in schools about HAES (Health at Every Size) and the dangers of over-exercise, dieting and restrictive eating
- A stepped care approach to treatment and support ensuring people get what they need at the right time
- A national campaign to raise awareness about an eating disorder being a mental illness, including myth-busting
- Add/improve the breadth of eating disorder content in current curriculum for mental health qualifications (e.g., psychology, counselling, Certificate 4 in Mental Health)

• Increased post-treatment support services and programs.

Conclusion

Through a two-step process, this lived experience engagement process has delivered a unique set of insights into how the system of care is experienced from a user perspective. Findings will be shared with key stakeholders in the eating disorder sector including government and non-government organisations, researchers, clinicians, and Butterfly's supporter base. Findings will also inform Butterfly's ongoing advocacy for greater investment in preventing, reducing and treating eating disorders and body image concerns.

Acknowledgements

Thank you to everyone with lived experience who participated in this engagement process.



JAYNE was in Year 12 when she started bingeing and restricting.

She found food to be comforting when she was stressed and the pressure of year 12 caused her to feel anxious and out of control. It is the following year and Jayne is becoming increasingly self-conscious.

She feels a lot larger than her friends and feels sure that people are talking about her appearance behind her back.

After a binge she often feels guilty, helpless, and disgusted with herself and then restricts her food for the next few days. Jayne often doesn't want to be social and is isolating herself, often canceling social activities where food is involved.

Jayne often eats in secret, in the car before she gets home from uni or in the locked bathroom at home.

Jayne is getting sick of the cycle, feels that it is affecting her studies and that she is losing friends. She recently saw a GP about an unrelated issue and the GP suggested she could try to lose weight.

Confused - conflicting advice

from health professionals

Emotionally exhausted

Sick of the cycle

Blaming herself

Isolation and shame

Scared and apprehensive

I can't do

this on my

own anymore

Researching signs and

symptoms online

Reaching out for information/support

Undergoing treatment

Finding treatment

Overwhelmed and lost where to get help or who to

Seeing descriptions of more severe behaviours - may feel "I'm okay" or "I'm not sick enough"

approach

May think her behaviour is just what people do to lose weight due to endorsement of disordered eating behaviours online

May not disclose due to stereotypes about what an eating disorder looks like

Service opportunity:

Mental health social media literacy so people can critically analyse content they see online

Wary - will they understand me?

Pain point:

Negative attitudes of medical professionals

Cost and practical concerns - do I need my own Medicare card?

Stigma and fear of judgement

Service opportunity:

Education for health professionals Training for medical students

What happens if someone from school sees me seeking help?

Frustration

Unsure – which therapies should I try?

Worrying about out of pocket costs

Concerned about fitting around exams and other commitments

Pain point:

Psychologist who does not adequately understand eating disorders

Shame when relaying experiences

Uncertain - will this actually work?

Service opportunity:

Provide easy access to information about effective treatments

Concerned about telling family and friends about treatment

Difficulty managing multiple treatments at same time differing viewpoints among health professionals

Thinking one good day means I am better

Ambivalence about treatment taking away coping mechanism

Isolatina

May seek treatment for something else (e.g., depression) as thinks may not be believed by health professional due to being in a larger body

Afraid won't maintain progress

Conflict with friends and family because of weight stigma feeling well, but still in a larger body so working out how to respond to external judgement

Dealing with external triggers

Acknowledging co-occurring mental health problems e.g., trauma that may come up after

Post treatment

Why do I still need support?

Service opportunity: Develop trauma-informed care

Am I actually recovered or in denial?

Managing responses to known triggers

Recovery

Service opportunity:

Promote more stories to support public awareness of recovery, including that recovery isn't always linear

Disappointed

additional care

Ashamed

Pain point:

Psychologist who does not adequately understand eating disorders

Feeling like a failure

Feeling stuck about accessing previous health providers or therapies – may feel embarrassed, but also scared about finding someone new

Might have developed another eating disorder to cope

Service opportunity:

Support group tailored to those with severe and enduring eating disorders

Service opportunity:

'Booster shot' program to top up prevention skills and strategies to help stay well in the long term

Following unhelpful diet advice - if believing weight loss is the answer

Not likely to reach out to family for fear of diet advice

Looking up places for help online

May defer taking action due to pressure of studies

Avoidance

Might have developed a different disorder

Shifting energy elsewhere with renewed enthusiasm

situations

Might revert to old behaviours in stressful Implementing new coping strategies Reading blogs or other resources

Getting involved in lived experience advocacy to help others Feeling free and more flexible in eating and other behaviours

More social interactions which include food



LEE is 15 and has been enjoying dance classes since she was 8 years old.

She has classes three times a week and has also been going to the gym for general fitness for as long as she can remember. Lee has started to feel that she is heavier than some of the other girls in the class. She also noticed a lot of posts on Instagram about the 'ideal weight' for dancers and perceives her body to be bigger than the dancers she follows and aspires to. Last year Lee decided to lose weight by following a low-calorie diet – at first limiting her intake a little bit. For the past couple of weeks, Lee has reduced her intake even further. Lee weighs herself every day. She does most of her exercise in her room at night, sometimes exercising to the point of exhaustion.

Lee's mother has noticed that she has lost weight. Lee's dance teacher has expressed concern to her mother about her recent weight loss and lack of energy in class.

Feeling attacked

What are the possible consequences?

May be thinking that relationship with exercise is healthy

Service opportunity:

Education on how to recognise and respond to signs and symptoms

Shame

Scared about will happen

Unsure what support looks like

Confused about how they got to that point and unsure of next

Denial

Seeking validation

Pain point:

Misinformation about what eating disorder looks like

Pain point:

People commenting/ complimenting on losing weight

Overwhelmed – where to go and where to start?

treatment

Scared of the journey and how hard it might be

Hopeless

May be feeling guilty or not deserving of help

Apathetic

Barriers to services might reaffirm the "I don't have a problem" mindset

> I don't have a problem

> > Pain point: Long waitlists

Frustrated

Feeling that life is on pause

Thinking she is "not sick enough"

Pessimistic about chance of recovery

Embarrassment

Overwhelmed

Shame

Anger Isolated

Pressure and expectation of others

Motivated

Hope



No agency

"All too hard"

Pain point:

Where treatment is involuntary

about topic

Eating disorder behaviours might intensify

Seeking help from family and friends

Aggressive behaviour towards carer

behaviours as consequence of not feeling"sick enough"

about behaviours

Learning new coping strategies (can be positive and negative)

Aggressive towards family and treatment team

Comparing progress to others

Not feeling ready

Lost

Discharge

Sad about people who gave up on her

Isolated

Anxiety into going back to social activities

Excited

Pain point:

Feeling unsupported by family

Service opportunity:

Interventions that support loved ones to sensitively handle concerns post-discharge

Unsure what next

Unsure if recovery is possible

Service opportunity:

More support for entering recovery phase

Service opportunity:

Provide more opportunities for lived experience advocacy

Free

Stable and more energetic

Grateful

Angry

Scared about going back to behaviours

Disappointed

Doing own research

Resisting treatment

Intensification of

Obsessive and protective

May go back to eating disorder behaviours, including more secrecy

New coping strategies emerge – potentially dangerous behaviours

Exercise is reframed as enjoyable activity

Getting involved in advocacy

Positive impact on life choices Socialising Re-engaging in dance

Acting on awareness of triggers Accessing ongoing psychological support

Proactive about protecting mental health, e.g., accessing identified supports when needed

Trying to avoid eating disorder behaviours by focusing on now familiar coping strategies

Accessing support networks



JIRO always felt large compared to his mates.

Growing up he was never really good at sport and his friends often joked – calling him 'budda' – but Jiro wasn't sure if this was because of his size or ethnicity. Living in a regional town as the only Asian kid at school he often felt isolated and tried to use sport as a way to fit in. As he reached high school, he started to notice lots of images on TV about thin but ripped guys who were athletic, popular and successful. He really wanted to slim down, so started going to the gym – at first once a week, but then more often, exercising at a higher intensity every time.

No matter how much he did, he didn't seem to gain as much muscle as some of his friends and felt as though he still had excess fat to lose. Recently Jiro started thinking that it was his calorie intake holding him back and has started purging whenever he doesn't eat what he thinks is 100% 'clean food'. Despite the weight loss and working harder and harder at the gym, Jiro still feels inadequate compared to his friends. He now spends all his free time at the gym, determined to get the body he wants.

Jiro's older brother is worried about him and has started doing some research online.

Just trying to just live a healthy lifestyle

Panicked

Conflicted within himself maybe feels it isn't the right thing but can't help it

Pain point:

Stigma because of his cultural background or/and because he is male

Fear of losing control

Shame around his behaviours

Feeling of relief

Sceptical of treatments that may help

Hopeful

Someone at the gym might recognise he has a problem and try and help

Service opportunity:

Resources for fitness professionals to recognise signs and provide assistance

See a GP or counsellor in his area

and reading online

Might approach someone who has

experienced something similar

Anxious about what support may be available

Many support services are far away as he is in a regional area

Pain point:

Care could be over 4 hours away

Accessing treatment as a man will he be believed? GPs may not have training around eating disorders or associate them only with women

Pain point:

GP who does not adequately understand eating disorders

Concern about being judged because he doesn't fit the stereotypical norm

Frustration because of limited resources - "Why is it so hard and what is the point?"

Pain point:

Difficult to find culturally competent services

Shopping around - who is

out there/who he can

access/who is qualified

and trained

Trying out clinics, groups,

one on one appointments

to see what fits

Anxious whether he made the right treatment choice

Fear that this is now real and acknowledging he has a problem

Being in a regional area may cause a barrier and make him question whether treatment is worth it

How long is treatment going to take? Will it fit into available Medicare sessions?

Worry around finances, travel time, logistics

Service opportunity:

Improve service provision in regional areas, including telehealth

Service opportunity: Fund care navigator roles

Can I afford treatment?

Isolated and disconnected if receiving treatment away from family and community

Scared

Angry

Could still be in denial - not fitting the stereotype might make him feel like he shouldn't be there

Afraid of disclosing to family and friends

Comforting to finally have some support and to find other people going through a similar experience

Pain point:

May be only man in an inpatient setting

Might be getting on a wait list

Entering into an agreement with a service

Developing a treatment

Telehealth sessions with psychologist

He could be an in-patient

Learning different coping strategies and challenging his beliefs and thoughts around food and exercise

Meal planning if seeing a dietician

Nervous to go back to normal life at home

Discharge

Relieved

Determined to take on board what he has learned and implement in everyday life

Worried about gaps in services. Will there be a gap between discharge and the next support?

Fear that he might fall back into old habits - will he remain well?

Service opportunity:

Develop more step-down care programs

Pain point:

Returning to an unhealthy environment - Jiro's friends might not be helpful considering he has been teased by them

Hopeful for the future and staying on the path of recovery

Post treatment

Getting on with life post-eating disorder.

Awareness that eating disorder thoughts can pop back up

May be feeling isolated if thoughts are persisting

Service opportunity:

Social and economic assistance to help create a life of meaning and purpose

Liberated

Unclear of the true meaning of 'recovery'

Having good and bad moments

Fear of relapse

Is full recovery possible?

Disappointed

Frustrated

Feeling like a failure

Shame and embarrassment

In denial

Planning –what other support and services are available

Setting boundaries with friends and families what is ok to talk about and what isn't

Having conversations with friends and families about ways they can support him

Linking with others who have been through similar experiences

Giving himself a lot of space from eating disorder communities and taking a break (e.g., from social media)

Assessing eating disorder thoughts, knowing you don't have to listen to them anymore

Separating the eating disorder from your

Aligning with his true values Creating goals outside of recovery

Deflecting concerns of loved ones Telling a friend or family member Reengaging with services and support

Hiding behaviours



JESS and Elissa met 18 months ago and moved in together after 6 months of dating.

When they met, Jess noticed that Elissa was very conscious of her appearance and spent a lot of time getting ready before going out, perfecting her make up and outfit for even the shortest outings. Jess just put it down to Elissa taking pride in her appearance. However, when they moved in together Jess noticed that Elissa was spending an increasing amount of time in the bathroom before going out, often having meltdowns about not having the right clothes to wear and calling herself names like 'tubby'. Elissa was also spending more and more time on Instagram, scrolling through endless posts of fitness influencers, and watching diet and weight loss 'success' stories.

More recently Jess noticed that Elissa's behaviour around mealtimes has changed. They used to love going out for dinner and brunch. In fact, being 'foodies' was one of the things they bonded over when they first met, but now Elissa seemed disinterested. These days whenever Jess gets home from work Elissa never wants to eat together and says she had already eaten despite there being no dishes in the sink. Elissa has started to lose more and more weight so Jess approached her about it, but Elissa became defensive and accused Jess of making an 'issue out of nothing'. Jess knows something is up with her girlfriend and is concerned that she is unwell.

Confused - is this something I should be worrying about?

Fear of losing person as a partner - fear that something is wrong with relationship

> Hoping someone else brings it up

Feeling trapped/guilty

Feeling a lack of trust from

Paint point:

Where do I find information that I can trust? How to filter to find the most suitable information?

Trying to understand the problem

Wanting to speak with a person who has experienced something similar

Feeling desperate

Strong need for information trying to find the right information

Service opportunity:

Develop dedicated resources for different types of family/carers (i.e., inclusive of partners, children)

Paint point:

Finding the right information and people to connect with among all the 'noise'

Helpless and fearful

treatment

Not being able to help

Burning out quickly

Feeling responsible for something you can't control

Fear of saying or doing the wrong thing or doing more damage

Paint point:

Difficulty finding the right type of specialist support

Paint point: Finding a whole team (not

iust individual elements) who can work together

Lacking indication of progress

Overwhelming feelings which may not be able to fully understand

Wanting a pathway and plan on next steps

> An alarm bell going off constantly which can't be switched off

Service opportunity:

More stories of treatment and recovery from a carer perspective

Constantly being unsure about whether it is the right thing/ feeling unsure and imagining alternatives routes

Navigating medical professionals who are saying unhelpful things

Resentful – feeling that your life has been taken hostage

> Wondering if recovery is possible



Dealing with consequences things you can't do/have anymore

Cycling from hope to despair and back

Service opportunity:

Unsure of role as a carer - frustrated and resentful

Undergoing treatment

How long will recovery last?

Discharge

Relief

Have done something awesome but also feeling nervous

Recovery isn't linear: dealing with back and forth

Nervous about how to re-integrate into social circles

Partner may feel protective or overprotective

Isolated: have gone through something which you had to go through but now what?

Paint point:

Being aware of triggering activities - how to avoid these?

Greater responsibility on you as a carer – less of a team around you

Post treatment

Service opportunity:

More support for family members and carers to manage ongoing recovery once treatment ends

Pain point:

Social media: How can the person you are caring for engage with social media in a healthy way?

Difficulty rebuilding trust

Being able to do things more spontaneously

Less fights

Recovery

Feeling more empathy and feeling heard/seen by other

More patient, having learnt more coping mechanisms

Noticing that the recovered person:

Is not thinking about food all the time

Eating intuitively

Is not counting or caring about ingredients

Is feeling more free

Service Opportunity:

Develop an app to support long term recovery, including rebuilding communication and trust Feeling as if you have

additional care

Scared for their health and for the journey that is ahead of you again

Disappointed, frustrated at yourself and the person

Angry

Exhausted

Pain point:

Carers become less important if someone is well and truly in recovery

Rediscovering yourself and partner and relationship – eating disorder masks behaviours, so you may meet a whole new side of the person (most often positive)

Wanting a way to be able to see that things are all good

Distrust/watching for cracks in foundation

Doing more research on new treatment approaches

Relationship dynamic changes if no longer carer

Broach the topic

Going to a support meeting to see what it is like

Attending online session about body image

Advocating for person experiencing illness

Shepherding person through differing periods of motivation

Accompanying to initial appointments

Accessing support groups to learn more as a carer

Seeking out others who are in similar situations.

Cleaning up broken dishes

Navigating other family relationships



Alex lives with their mum in a suburb of a capital city.

Alex has preferred boys' clothes, toys and interests since early childhood. In Year 1 they begged their mum to cut their hair short and refused to wear dresses and skirts as part of their school's strict uniform dress code. Primary school was a difficult time, and Alex was picked on for being a tomboy and having more friends who were boys. At age 11 when Alex started going through puberty, they started feeling very depressed and tried everything they could to feel better in their body, including restricting their food intake.

Now aged 12, Alex has told their mother that they would like to be affirmed as a boy and begin a process of blocking puberty. Their mother is broadly supportive but is more concerned about the very sudden change to Alex's eating habits and his depression. After several weeks of discussing this issue, Alex and their mum agree to seek some professional help but are unsure of where to start. The bullying that Alex has experienced from their peers has made them feel worried about the potential for discrimination from health professionals.

Feeling accepted

Feeling safe

Proud

Powerless

Trapped

Pain point:

Not seeing body reflected in what a person with an eating disorder 'should' look like

Still feeling scared and unsafe

Shame

What treatment is available?

Pain point: Not being treated seriously due to being 'normal' weight

Shame

Hopeless

treatment

Dealing with wait list

Pain point:

Not enough treatment options available

Hope

Exhilaration

Desire to get better, but feeling unsafe and uncertain

Financial concerns of parent about cost of private care treatment in public system may not be trans informed

Pain point:

Financial constraints and worries

Service opportunity:

Ensure treatment is safe and effective for trans people

Overwhelmed

Motivated

happen

Accepting of being gender diverse and that the eating disorder was a way to gain back control

Managing compliments about weight

Service opportunity:

Promote body positivity a narrow range

Trauma symptoms if accessing

Asking for help

Battling to access

Understanding change must

for all bodies in recovery - not just for those within

> May initially revert back to problem behaviours

Discharge

Scared

Anxious

Worried about what ongoing

support is available

Service opportunity:

Post-discharge support

program, including

practical and social

support for trans and

gender diverse people

Experiencing symptoms of trauma if have had poor care experiences

Normal eating resumed

Post treatment

Flat

Able to reach out for assistance,

but still anxious

Parent wondering if can afford

to seek help again

Engaging with LGBTQIA+ community to access informal support Making friends with other trans kids

Socially connected

Out of control

difficult for them

Little concessions which can spiral into unsafe behaviours

Needing community for support

Increasing unhealthy behaviours as a way to prove 'sick enough' to access help

Getting sicker and presenting as gender assigned at birth so that concerns will be taken seriously

Unhealthy behaviours such as restricting could become worse

treatment that is not informed about eating disorders or transgender issues

Exhibiting unsafe behaviours

appropriate care