



Lived experience
journeys through
**the eating disorder
system of care**



Contents

Background	3
Overview of the current eating disorder system of care	3
Challenges in seeking treatment	5
About the Lived Experience Community Insights Group (LECIG)	6
The journey mapping exercise	6
Methodology	6
Findings	6
Top two barriers to care	7
Top six advocacy priorities	8
Lived experience advocacy priorities	8
Conclusion	8
Acknowledgments	8
Appendix – Journey maps	9

Suggested citation: Butterfly Foundation. (2022). Lived experience journeys through the eating disorder system of care. Report of journey mapping workshop with the Butterfly Foundation Lived Experience Community Insights Group.

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

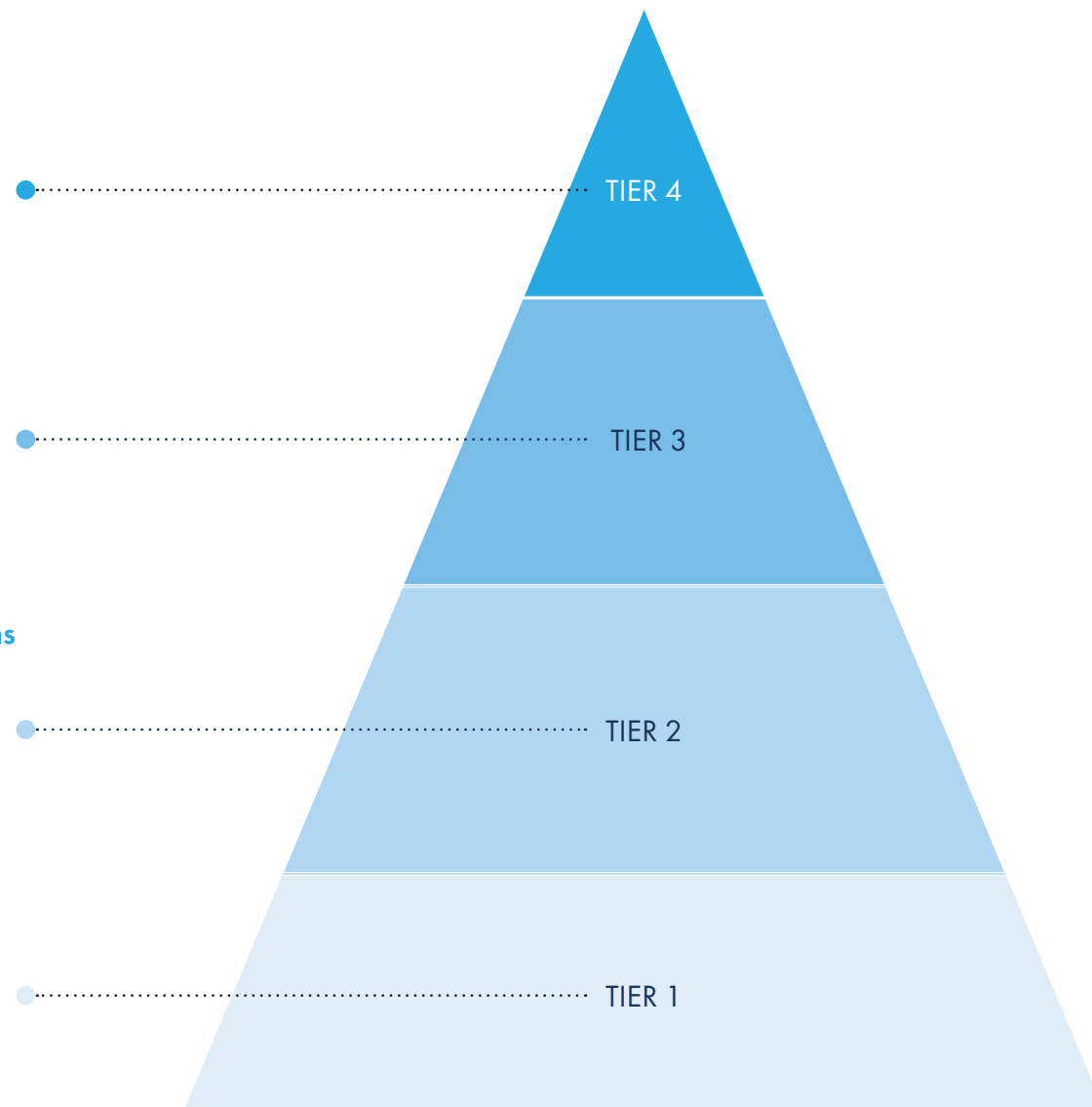
Schools

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

The 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 through:

- 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 as being 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 LGBTIQ+ 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 over-exercise 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.



Persona 1

JAYNE

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.

Need (identifying the need for help)

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

Reaching out for information/support

Overwhelmed and lost – where to get help or who to approach

Seeing descriptions of more severe behaviours – may feel “I’m okay” or “I’m not sick enough”

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

Finding treatment

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?

Securing treatment

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

Undergoing treatment

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

Discharge

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

Post treatment

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

Why do I still need support?

Service opportunity: Develop trauma-informed care

Recovery

Am I actually recovered or in denial?

Managing responses to known triggers

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

Relapse/Need for additional care

Disappointed

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

Isolating

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

Might have developed a different disorder

Shifting energy elsewhere with renewed enthusiasm

Might revert to old behaviours in stressful situations

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

Researching signs and symptoms online

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



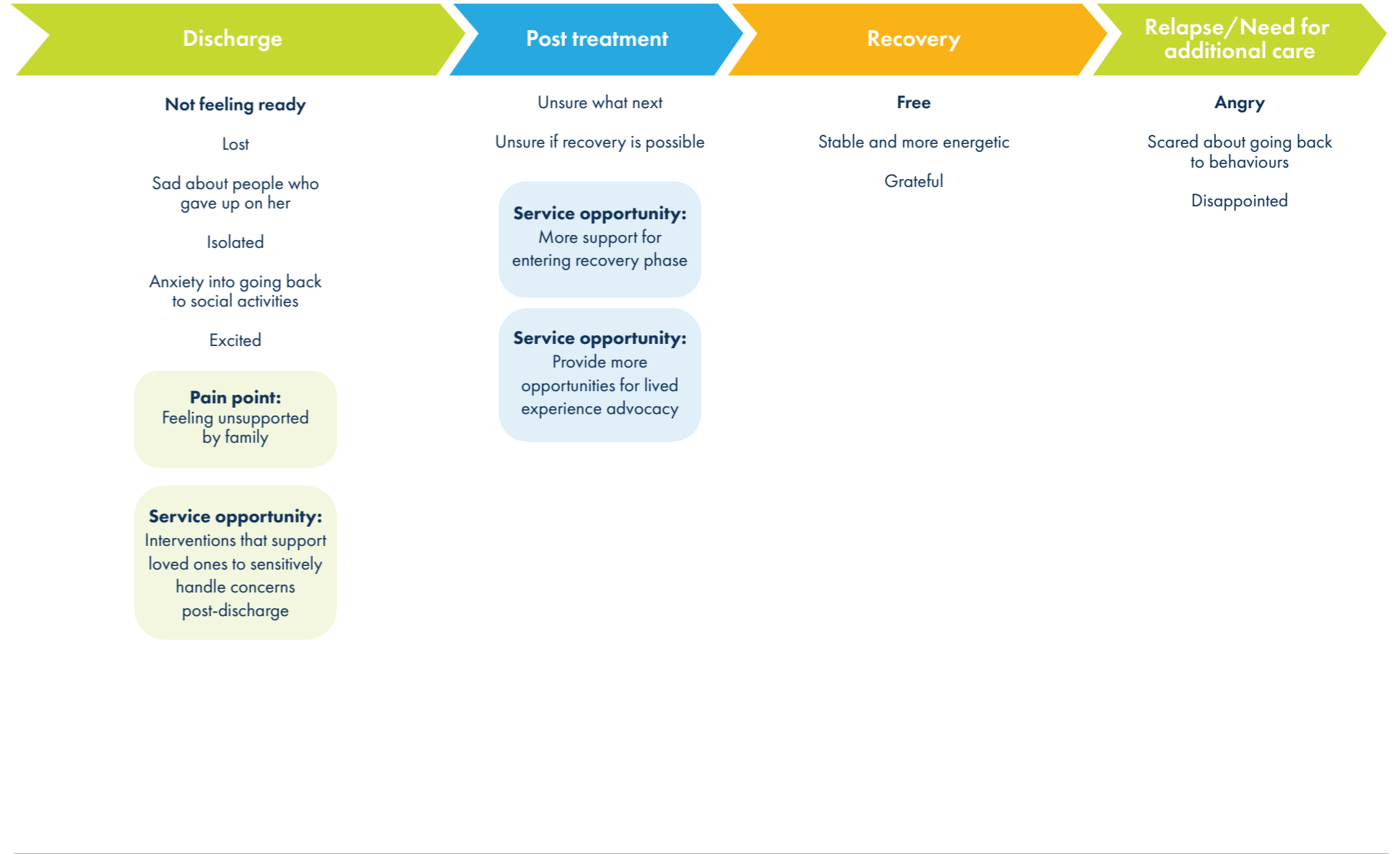
Persona 2

LEE

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.





Persona 3

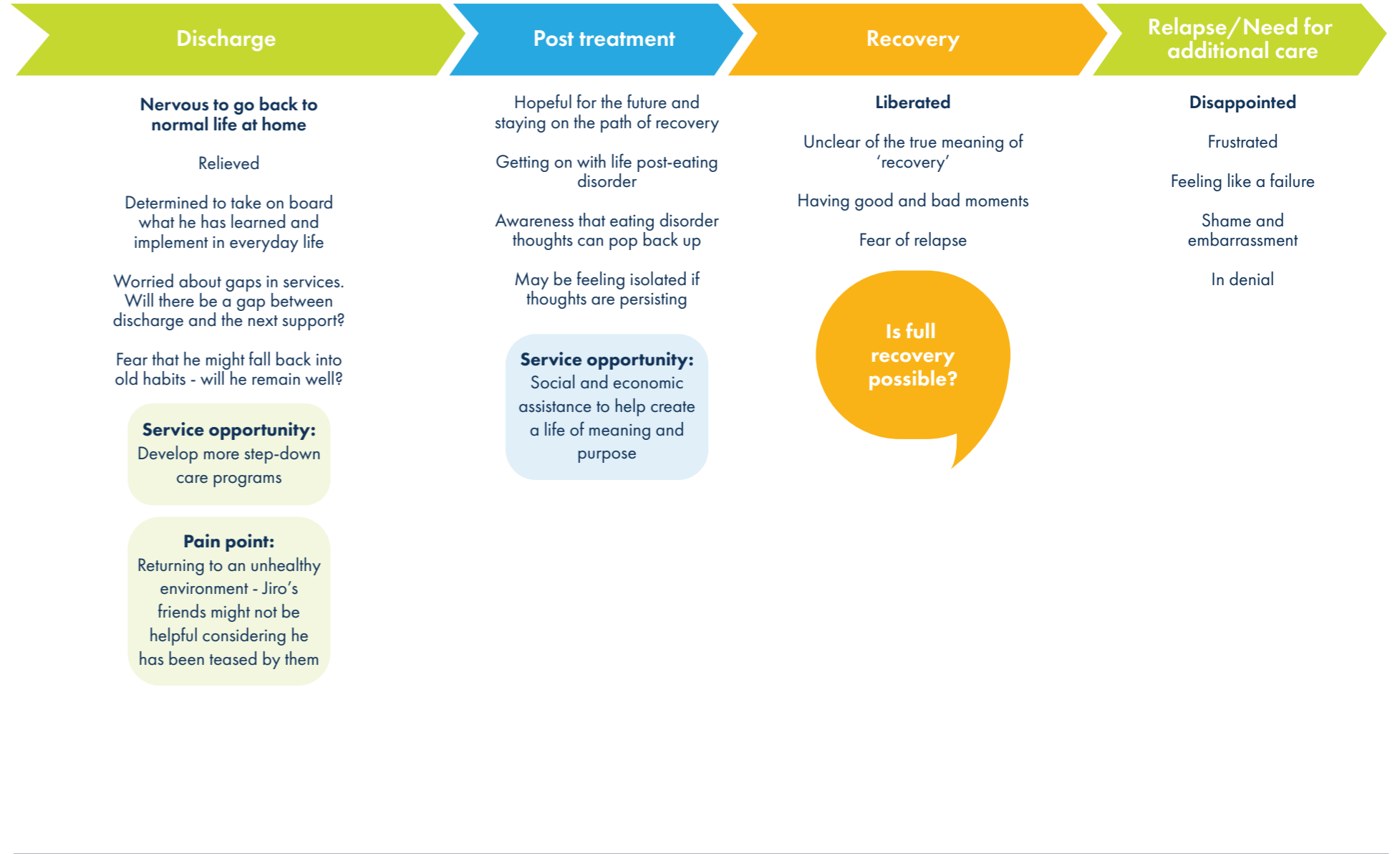
JIRO

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.





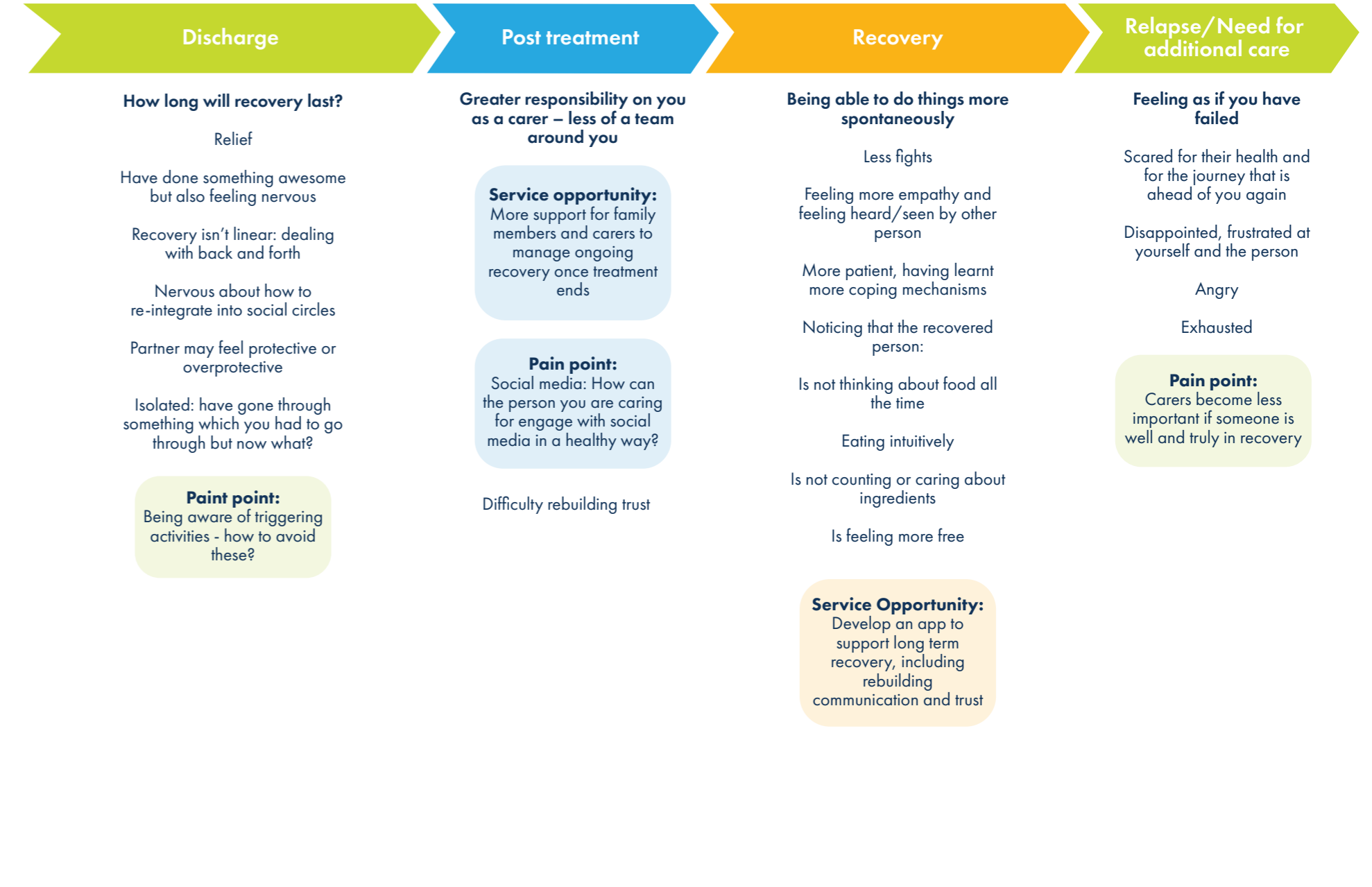
Persona 4

JESS

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.





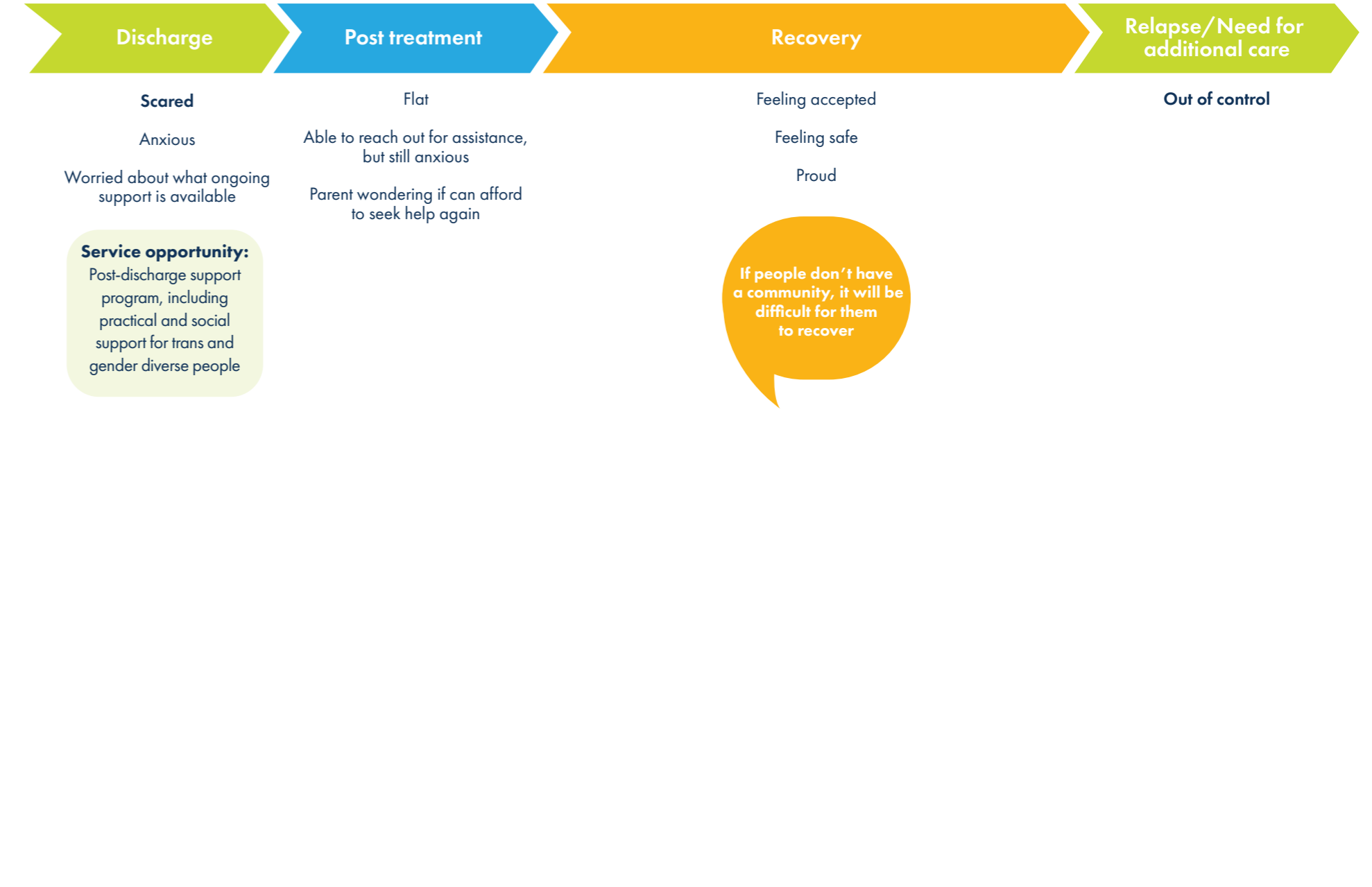
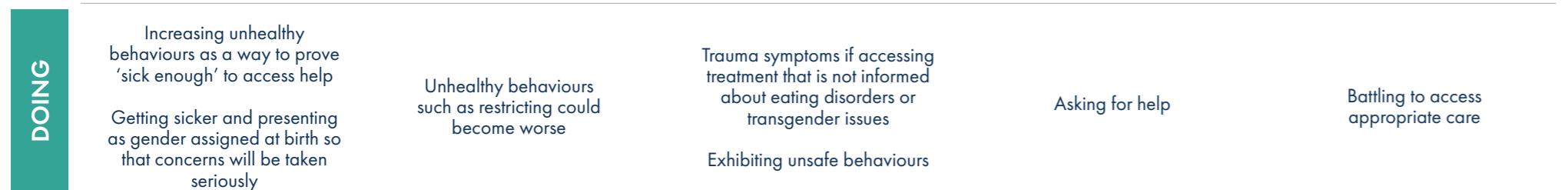
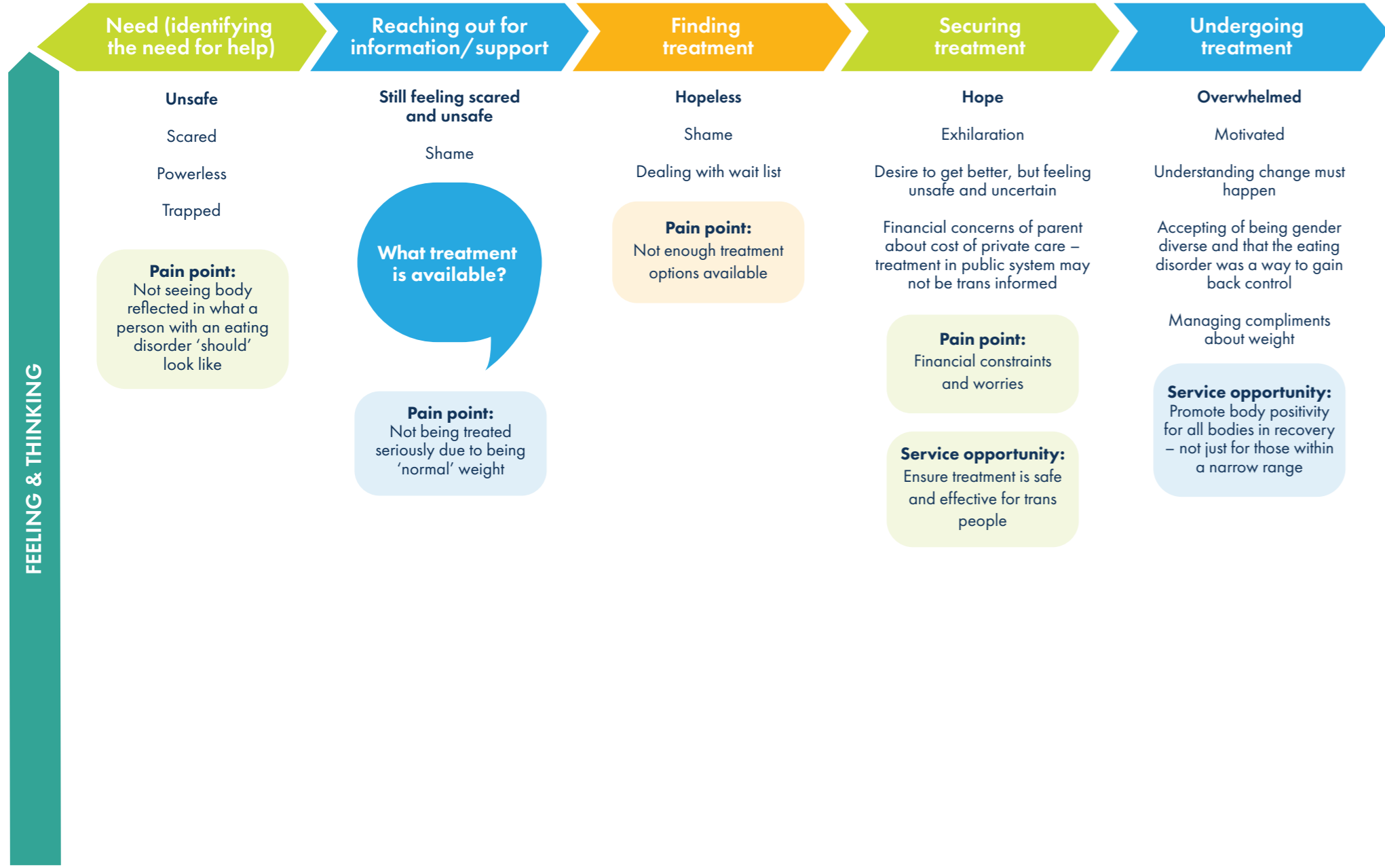
Persona 5

ALEX

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 & THINKING

DOING