

Tracing Autonomy

Produced by Jeni Pearson and Kirsty
Stansfield in consultation with
Prof. Ben Colburn.

Framework Guide

Contents

1. Introduction	03
2. The Holistic Terrain	06
3. Characteristics of Autonomy	09
Choice	11
Value	13
Relationships	15
Authorship	16
4. Threats and Ideals	17
5. How to use the Tracing Autonomy 4 Step Method	20
6. Visual Summary	23

Introduction

1

Introduction

Tracing Autonomy offers a systematic way of reflecting on practice that is appropriate, efficient and focused.

It is not a form to fill in, instead Tracing Autonomy offers:

1. A 4-step process that can be tailored and adapted to practice and in relation to the person you are working with.
2. A workshop that brings together theory and practice to support learning through an embodied creative experience.

Autonomy is an ideal of a good life for human beings. The autonomous individual is the author of their life. They decide for themselves what is valuable, and live their life in accordance with that decision.

Autonomy is a relational ideal. The autonomous life is not isolated or self-sufficient. It is lived through supportive and reciprocal relationships with others, and with society in general.

Autonomy is an ideal that can be realised in many ways. It recognises the truths of neurodiversity and differences in people's physical and mental capacities. Individuals decide for themselves how to self-author given the parameters of their own lives, and their own values.

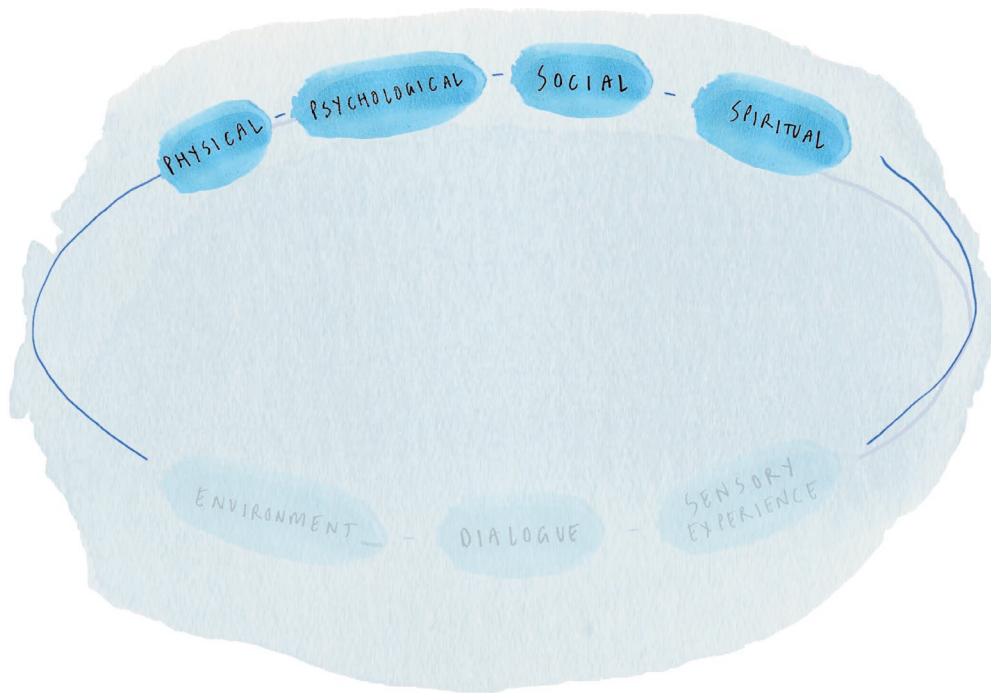
That is why Tracing Autonomy is not a blueprint, but an invitation for reflection about the different ways we can support autonomy.

The Tracing Autonomy Framework guides you through an expanded holistic terrain, the four key characteristics of autonomy and outlines how to identify possible threats to and ideals for a person's autonomy. It brings these components together in a practical four-step method that uses autonomy to underpin practice.

The Holistic Terrain

2

The Holistic Terrain



Tracing Autonomy expands on the holistic assessment commonly used within palliative care. This offers a holistic overview that highlights the concerns or issues a person may have. The insight this provides enables practitioners to explore how these issues might affect a person's autonomy.

This holistic approach takes into account the physical, psychological, social and spiritual aspects of a person's life. It also considers the **environment**, quality of **dialogue** and **sensory experiences** that a person may have.

Physical

This encompasses all physical aspects of a person's life, their current health, their medical history and symptoms relating to medication or treatment that impact on the body.

Psychological

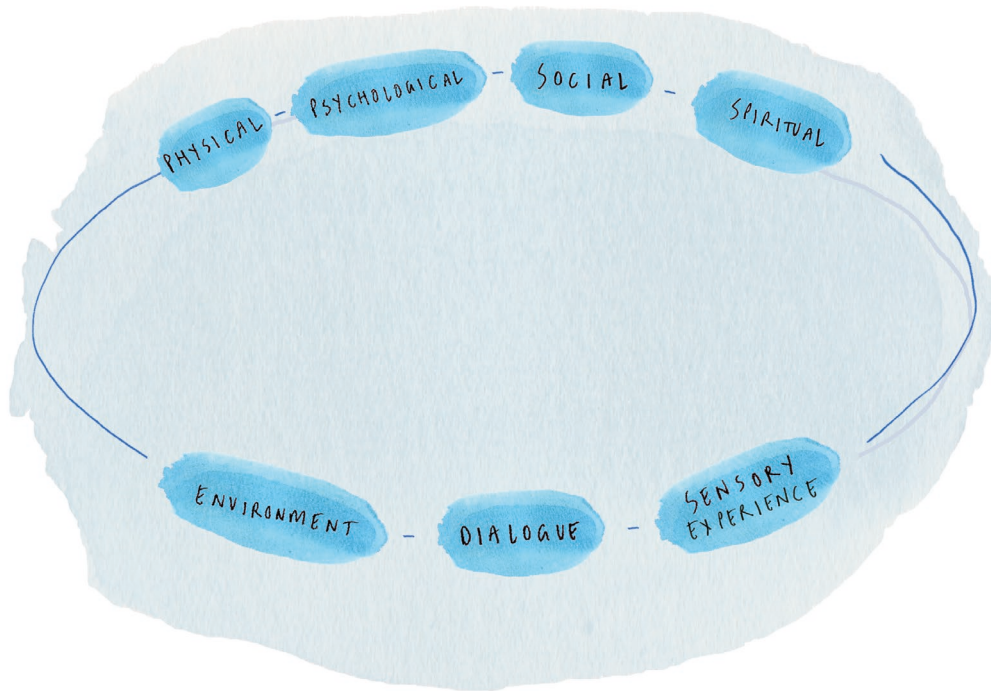
A person's current emotional state and any pre-existing aspects of the emotional self.

Social

An individual's situation in relation to society and their ability to interact with this and others, for example: housing, financial status, access and the relationships that a person has.

Spiritual

A broad concept that includes a sense of connection to something bigger than ourselves and typically involves a search for meaning in life.

**Environment**

Our physical environment can influence how we behave, its impact can be quite subtle or more obvious at times. Environment extends to our home, place of care, work, the street we live on and the city in which we live. How does an environment support or undermine a person's autonomy?

Dialogue

We know good communication is important. How often do we think about the quality and nuances of that dialogue?

What factors might be influencing dialogue? Who else is in the room? What is being communicated non-verbally? Are we actively listening?

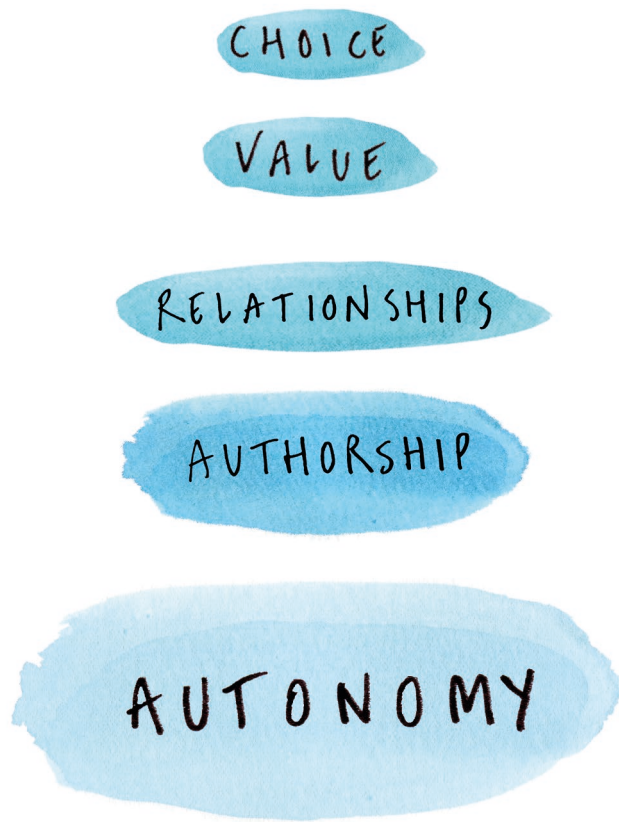
Sensory experience

We all have specific sensory needs to support an experience or interaction. Paying attention to sensory experience can help build trust. It acknowledges that people understand the world and process information around them in a multitude of different ways. Consider how and where information is presented and received. The details matter!

Characteristics of Autonomy

3

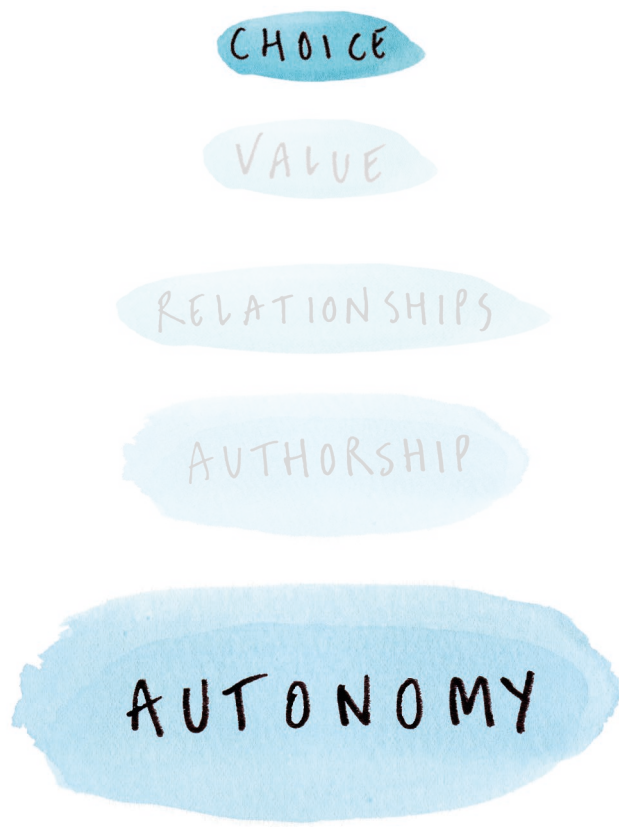
Characteristics of Autonomy



The concept of autonomy can be simplified into four characteristics: **choice, value, relationships** and **authorship**.

These characteristics help frame a way of thinking about a particular experience and enable us to consider whether or not an interaction or situation was in support of a person's autonomy or not. Looking at these characteristics in relation to the holistic terrain can help us understand how a person's autonomy is being affected positively or negatively.

Choice



Choice is the act of choosing between two or more possibilities. In relation to a person's autonomy it does not always mean having the freedom to choose. In fact having too many choices can be a threat to a person's autonomy.

When we think about choice, consider the conditions under which those choices or decisions are being made. It is important to understand whether or not the choices presented are voluntary or not.

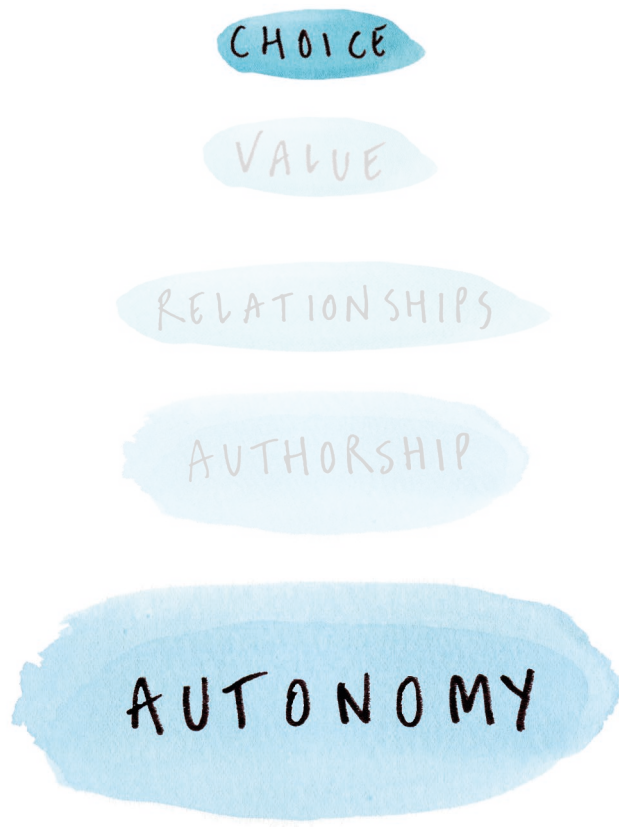
To explain this further, imagine a highwayman is holding you up at gunpoint and saying, 'It's your money or your life'. You can make a choice here, but your choice isn't voluntary because you wouldn't actively choose either option for yourself.

This is a good example of an involuntary choice and we can compare this to the experience of a person living with a life-limiting illness who is offered the choice of treatment, that comes with its own risks and detrimental side effects, or the alternative which is to decline treatment and to have a more likely shorter life expectancy.

Another consideration is whether or not choices are informed? Do people have the information they need to be able to make decisions in relation to what they hold most valuable?

How are we presenting choice and how active are people in identifying options and choice for themselves?

Choice



For example:

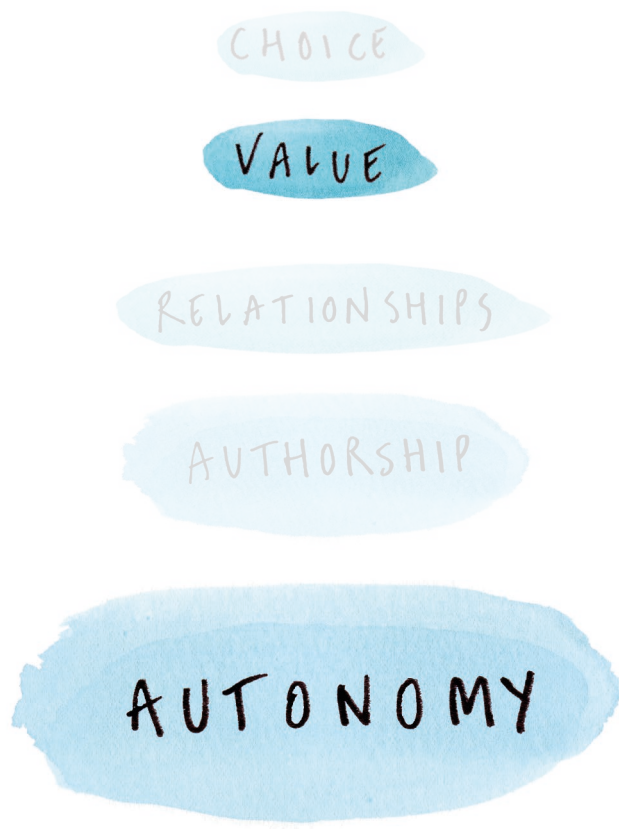
Statement: "Since my diagnosis I don't feel like I have options or choices anymore. I would choose not to have this illness."

Response: "I can't change your diagnosis, but I can work with you to help you find a range of options in relation to what matters to you and with what is available."

Statement: "Making decisions has become really hard for me since becoming unwell and I feel like I don't have control over my life anymore."

Response: "I can help source the information you need to help you to be realistic and make informed decisions that relate to your life. Hopefully this will help you to feel more in control."

Value



Values are the principles or standards of behaviour, your own judgement of what is important in life. In other words, what matters to you?

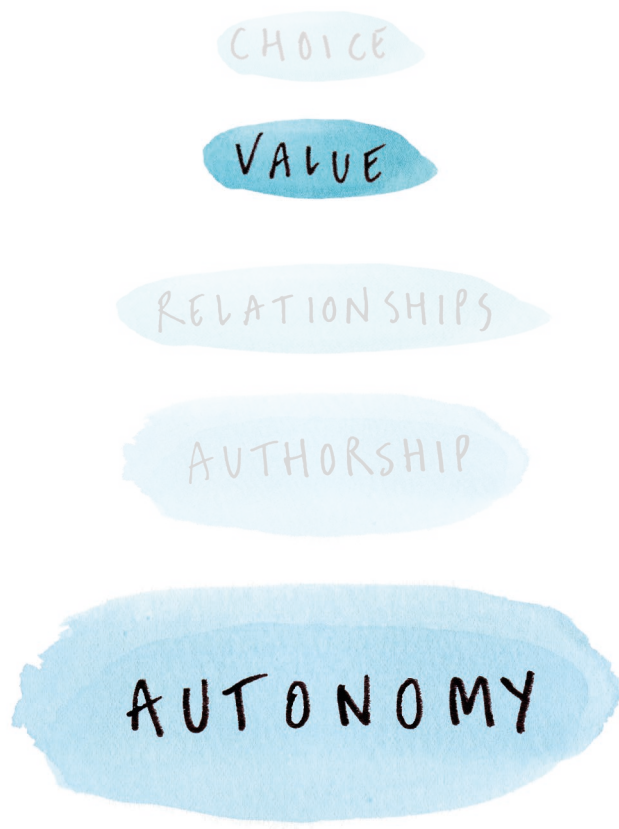
This question is already widely used within palliative care. To ask this within the sector is accepted as good clinical practice.

How can a person maintain their values when faced with the challenges of a life-limiting illness? What matters may change as a person becomes less well.

As a professional what you consider to be best practice may differ from the values of the person you are supporting.

"By placing an individual's values at centre stage ensures that the delivery and balance of the holistic components are structured around the core ideal of self-authorship." Ben Colburn

Value

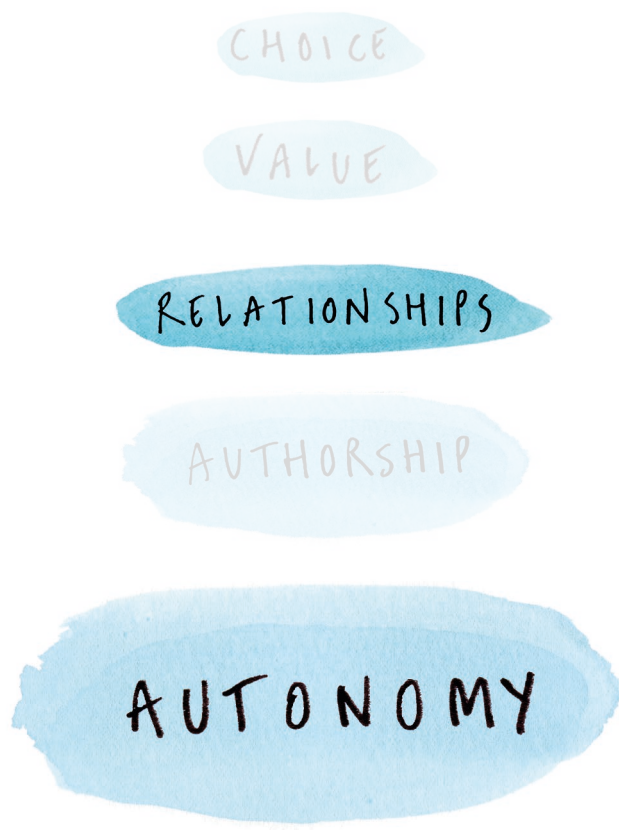


Statement: "I value my morning cup of coffee. I like real coffee not instant and I like it strong, with milk in a mug and not a cup. It sets me up for the day and I don't feel right if I don't have it."

Statement: "I value my relationships with my children – I want more time to experience things with them, beyond the day to day. I worry that I will miss life events, like when they learn how to ride their bike or swim a length in the pool, graduate from school or college, get married or have children of their own. It's difficult because I am not in control of this and it makes me very sad."

Statement: "It matters to me that I am still able to get out and see my friends. We meet twice a week in our local pub to watch the football. I have been told that I should avoid alcohol, but I feel embarrassed about this because not all of my friends know that I am unwell. I don't like to talk about it, that's just not what we do."

Relationships



Relationships are the way in which two or more people, or things are connected, or the state of being connected.

Relationships can change when a person is faced with a life-limiting illness. What is it like to be cared for? To be cared for is not always an intrinsically 'good' thing, it can disempower as well as empower.

Often when faced with a life-limiting illness people no longer feel able to contribute or give something back. How can we ensure that a person still has the ability to have influence, to have a voice and for that voice to have an effect?

Key to autonomy is being able to forge reciprocal moral relationships (of trust, care and need) with others, to help shape their lives and to let them shape ours too. (Ben Colburn)

In professional practice clear boundaries are important, but this doesn't mean that we can't form rich relationships with the people we work with. It doesn't have to be all or nothing. It is how we configure these relationships in relation to the needs of the individual within our care that can either work in support of, or undermine a person's autonomy.

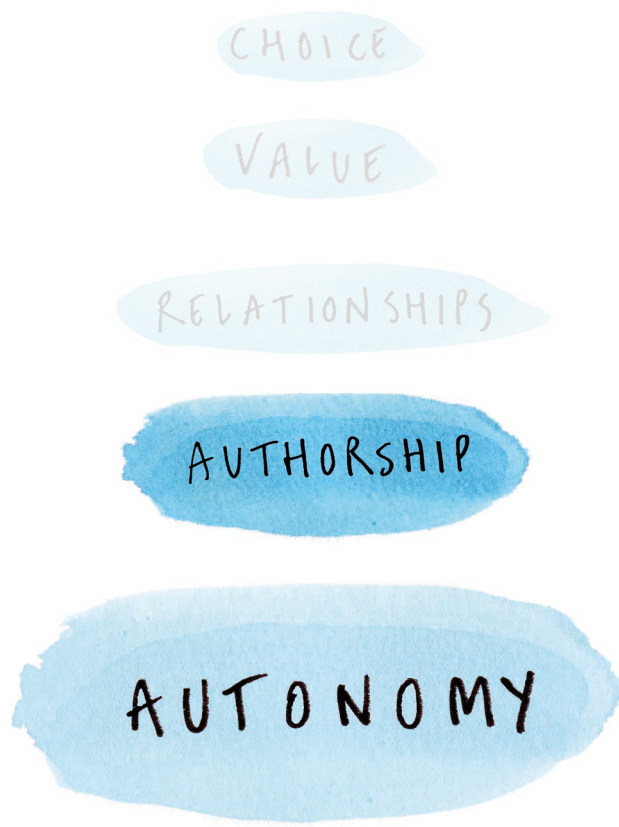
Statement: "I want support with making decisions from my doctor."

Statement: "I want to be in control of decisions that will impact on my life."

How you practice can adjust in relation to the person that sits in front of you, one size does not fit all.

When we act as connected to another person, as opposed to separate, does this mutuality support or undermine a person's autonomy?

Authorship



By bringing together the elements of choice, value and relationships, an individual can enjoy the fourth aspect of autonomy, successfully being the author of your life.¹

To be author of your life is important at any stage, but particularly when so many other things are closing down through illness, disability or social circumstances.

It is vital to find ways that people can still grow and achieve, but in ways that that are meaningful to them. Being involved in decision-making and having the information you need to make informed choices supports a person in being author of their own life.

Having the opportunity to be creative and to learn new skills supports a person to literally be an author and to produce new knowledge from within her or himself. Once created this is something that can be shared with others. For example: a piece of visual art, a written or spoken work, an imagined image, a gesture or movement, a piece of music, a home-baked cake, a perfectly brewed cup of tea, a knitted scarf or a beautiful garden. These activities create meaning and support a range of relationships that recognise an individual's values and choices in life.

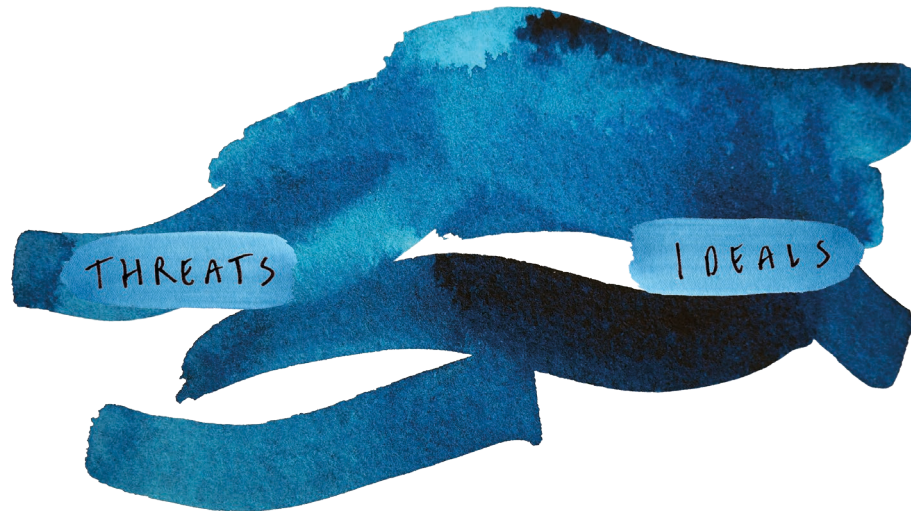
A creative process does not mean that anything goes. Constructive parameters and constraints can promote autonomy when tailored to a person's values, choices and relationships. This is achieved by paying attention to the wider context and the embedded relationships within the situation for each individual.

1. The idea of self-authorship comes from the philosopher Joseph Raz, and was developed further by Ben Colburn.

Threats and Ideals

4

Threats and Ideals



Once we consider the wider context of what is going on for a person within the holistic terrain we can identify what factors are working in support of, or as a threat to a person's autonomy (in terms of choice, value, relationships and authorship).

Identifying the things that work in support of autonomy can help a person position themselves in a way that reflects their own values. This enables the person to identify realistic goals and to work towards achieving these – by being author to their own life.

Ideals and solutions are not the same thing and there can be conflict between an ideal and the options available. How can you address this in a way that supports autonomy?

Statement: "I want to die at home, but my family are struggling to cope with my growing care needs, I don't want to be a burden to them."

Response: "Can I facilitate a conversation with your family where you can express your preference and give your family the opportunity to express what they feel able to support? We can then discuss what could be put in place to support your preferred place of death."

It should be noted that there is also a risk that a patient's ideal does not always align with what is best practice for the practitioner:

Statement: "I am not going to stop smoking."

Response: "It is my professional opinion that you would benefit from being on oxygen, but because you have made a choice to continue smoking this is unsafe for you to use. Oxygen will not be available to you as long as you continue to smoke."

The Tracing Autonomy Framework can be used to help rethink a situation in which the ideal may not be possible, but an alternative may be acceptable.

For Example:

A patient nearing end of life is no longer able to get out of bed:

Statement: "I don't want to be stuck in this room, I want to be in my garden and feel the fresh air."

The threat to this person's autonomy is that their desire to be outside is no longer safely possible. Instead of saying, "No", is there an alternative? What needs to be in place for this to happen?

Response: Can the bed be taken outside safely? And if this isn't possible, can we bring the outside in? We could open the windows, bring plants inside, soil or flowers. What would you like to see or smell? What would you like to touch?

How to use the Tracing Autonomy 4 step method

5

The Tracing Autonomy 4 step method

This method is useful when a session with a patient/ client/ individual was particularly difficult or significant for one reason or another.

Step 1:

Clearly and simply outline what that experience was. For example: What was significant? Who did this involve? Where did it happen? Who else was in the room? What happened prior to, or after this particular instance?

Step 2:

Use the holistic terrain to consider what factors made the session significant or influenced it in some way. Maybe it was a combination of more than one of the holistic factors? Or maybe it was something else that is not captured within the terrain?

Step 3:

Consider the characteristics of autonomy: choice, value, relationships and authorship. Use these characteristics to understand how a person's autonomy has been affected positively or negatively. This can help illustrate how an experience has worked in support of or against a person's autonomy.

Step 4:

In conversation with the person you are supporting discuss what the threats to their autonomy were in that situation and what their ideal would be. Bearing in mind that the ideal may not be possible, explore options that work towards an acceptable solution.

With Thanks

We would like to thank the people who have generously given their time, guidance and support with this project. Without their support Tracing Autonomy would not have been possible.

Prof. Ben Colburn, Head of Philosophy,
University of Glasgow

Rhona Baillie, Chief Executive, The Prince &
Princess of Wales Hospice

Dr Alistair McKeown, Palliative Care Consultant,
The Prince & Princess of Wales Hospice

Gillian Sherwood, Director of Clinical Services,
The Prince & Princess of Wales Hospice

Fiona Wylie, Senior Nurse for Strategy
Implementation, The Prince & Princess of Wales
Hospice

Sharon McCaffrey, Out Patient Sister,
The Prince & Princess of Wales Hospice

Carol Graham, Family Support Services Manager,
The Prince & Princess of Wales Hospice

Liz Smith, Practice Development Facilitator, The
Prince & Princess of Wales Hospice

Members of the Research Group, The Prince &
Princess of Wales Hospice

Janette McGarvey, Young Person's Development
Worker, The Prince &
Princess of Wales Hospice

Audra Cook, Clinical Governance
Co-ordinator, The Prince & Princess
of Wales Hospice

Sharon Goodlet, Artist, The Prince & Princess
of Wales Hospice

Paul Hart, Sense Scotland

Liam Campbell, Practice Development Lead
(Health), Enable Scotland

Louise Briggs, Arts & Heritage Officer, Studio
Pavilion at House for An Art Lover

Bob Carey-Grieve, Community Hub Team
Leader, Saltwater Promenade Community Centre,
Melbourne

Marielle MacLeman, Artist

Charlotte Donovan, Arts for Health Development
Worker, Niche Community Health Project, Cork

Sarah Ruttle, Artist

Claire Meaney & Maeve Butler, Waterford
Healing Arts Trust, Waterford

Barbara McEwan Gulliver, Artistic Director, Art
in Hospital

Laura Flynn, Graphical House

Kim Walker

Dr. Simon Yuill

Matt McPhee

The Mitchell Library

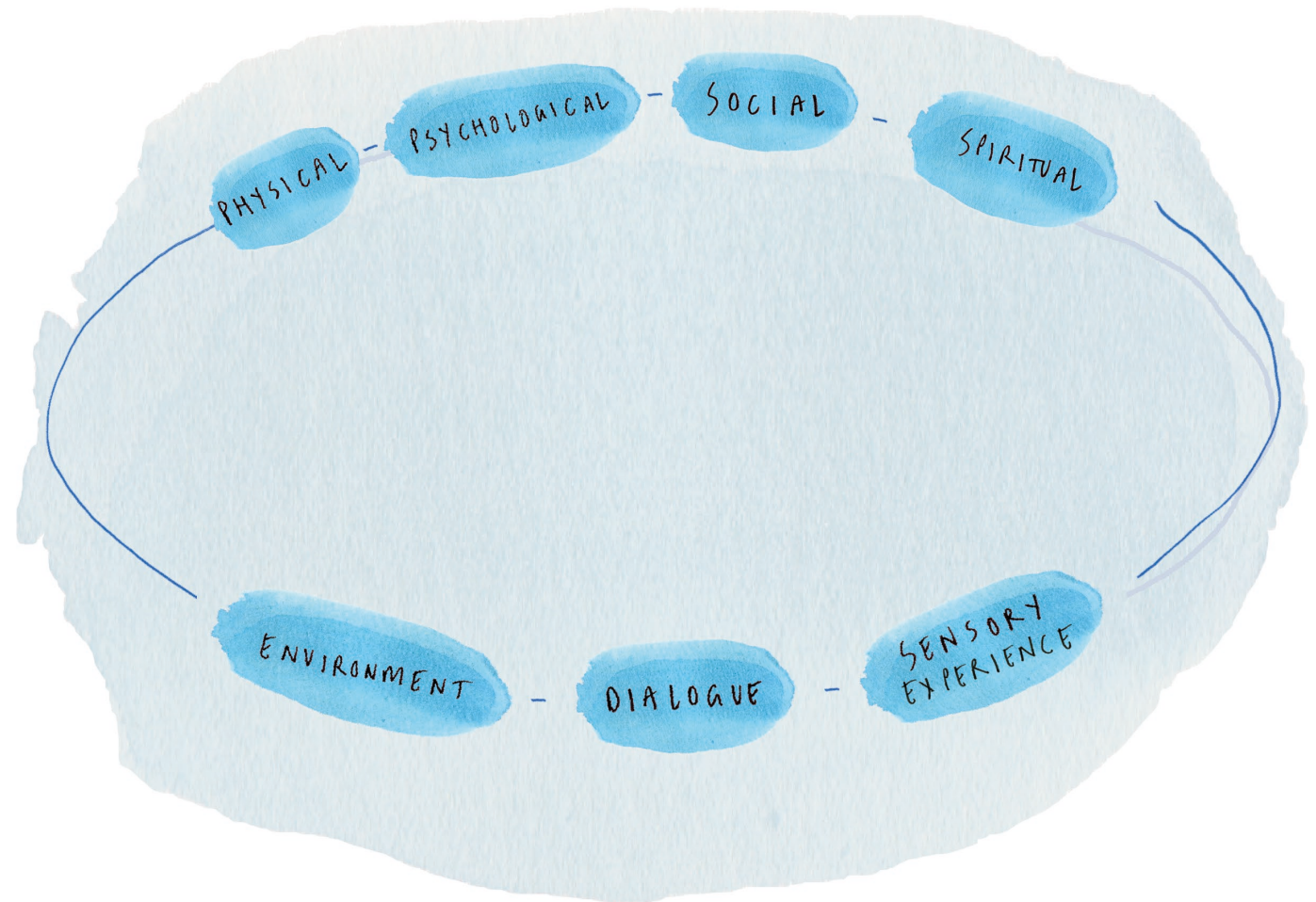
Willow Café

Visual Summary

6

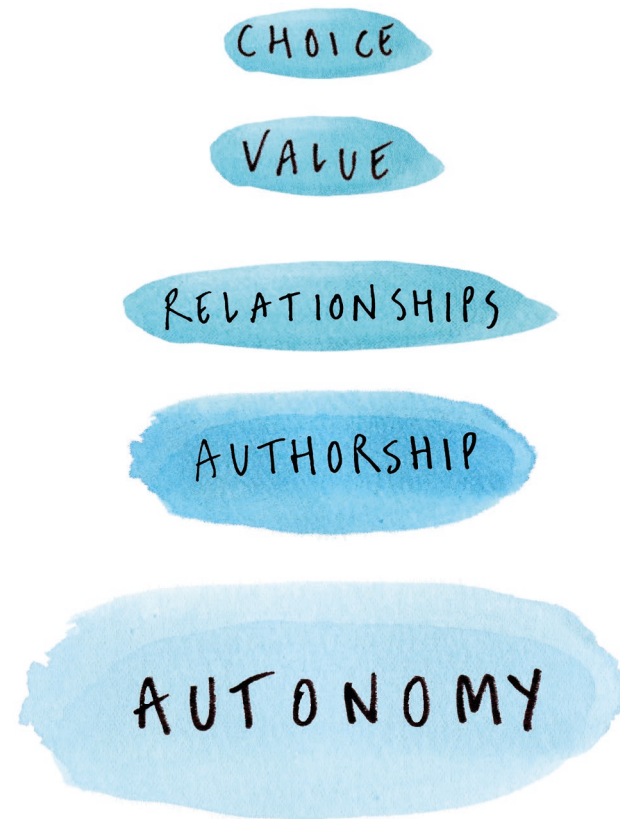
The Holistic Terrain

This holistic overview highlights the concerns or issues that a person may have and how these factors might affect a person's autonomy.



Autonomy

The concept of autonomy can be simplified into four characteristics: choice, value, relationships and authorship. Considering these characteristics in relation to the holistic terrain can help us understand how a person's autonomy is being effected positively or negatively.



Threats and Ideals

What are the threats and ideals for the person you are supporting?



Tracing Autonomy

Contact us

autonomy@tracingautonomy.net
www.tracingautonomy.net

Tracing Autonomy has been made possible with support from **The Prince and Princess of Wales Hospice** and a Knowledge Exchange and Impact Award from the **University of Glasgow**.



University
of Glasgow



The Prince & Princess
of Wales Hospice