

# Is self-compassion the antidote to diabetes stigma and distress?

Dr Adriana Ventura

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# Overview

- **Part 1: Research**

- What does psychology have to do with diabetes?
- Key and emerging areas of psychosocial research in diabetes
- Diabetes MILES findings

- **Part 2: Practice**


- Self-compassion as a focus for diabetes management
- What you can do

# Living successfully with diabetes

- In-target average blood glucose levels
  - HbA1c <7% or <53mmol/mol
- Preventing or delaying complications
- Longer diabetes duration
- Scrupulous self-management
  - Healthy eating, regular physical activity, taking insulin/medications as recommended
- Social and occupational functioning
- Emotional well-being
- Quality of life

# Living successfully with diabetes

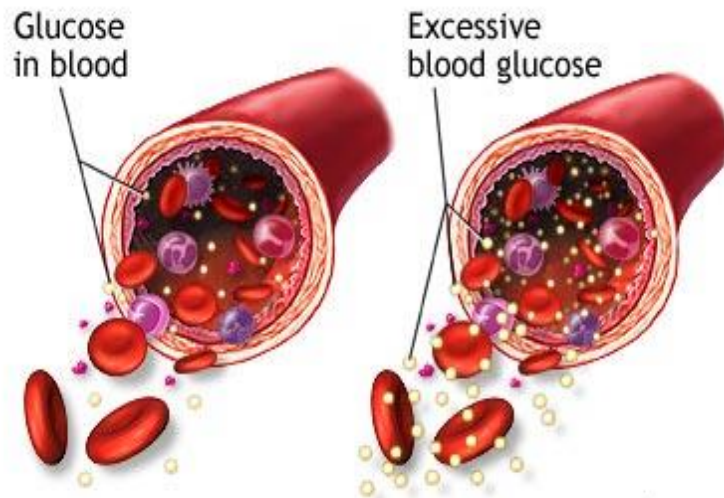
- In-target average blood glucose levels
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- ~~Preventing or delaying complications~~
- ~~Longer diabetes duration~~
- ~~Scrupulous self-management~~
  - ~~Healthy eating, regular physical activity, taking insulin/medications as recommended~~
- ~~Social and occupational functioning~~
- ~~Emotional well-being~~
- ~~Quality of life~~



Surely success is  
all about achieving  
HbA1c targets



# What does HbA1c tell us?



- Measure of average glucose levels in the past 8-12 weeks
- Strong association between HbA1c and risk of complications
- A reliable indicator of future health

# What doesn't HbA1c tell us?

- about everyday highs and lows
- how the person manages their diabetes
- knowledge of diabetes
- beliefs about diabetes
- self-management skills
- confidence
- the support (or lack of it) from family and friends
- how diabetes affects quality of life
- how they feel about living with diabetes



# The intersection of diabetes and psychology

*“From a psycho-behavioural perspective, it is difficult to imagine any other illness that places the same level of demand on patients to self-monitor and self-regulate their own health status”*

Gonder-Frederick LA et al. Diabetes and behavioural medicine: The second decade. Journal of Consulting and Clinical Psychology 2002;70(3):611-625.

*“State-of-the-art diabetes care builds on psychological and behavioural principles, not for only those patients with psychological disorders, but for all persons living and coping with diabetes.”*

Skinner TC & Snoek F. Psychology in diabetes care, 2<sup>nd</sup> edition 2005; West Sussex, UK: Wiley. p. xvii

***“The evidence that behaviour is the dominant element in successful management of diabetes is so overwhelming that we tend to ignore it”***

– Professor Edwin Gale



# Self-management is complex

- It is a behavioural process
- Shift from *adherence* → *empowerment*
  - Provide people with the skills, resources and support they need to make informed self-care choices
- Self-management influenced by a range of individual, environmental and social influences
  - E.g. attitudes, beliefs
  - Psychological wellbeing, QoL
  - Social supports/relationships/work or school context
  - Interaction with health professionals

# Diabetes MILES

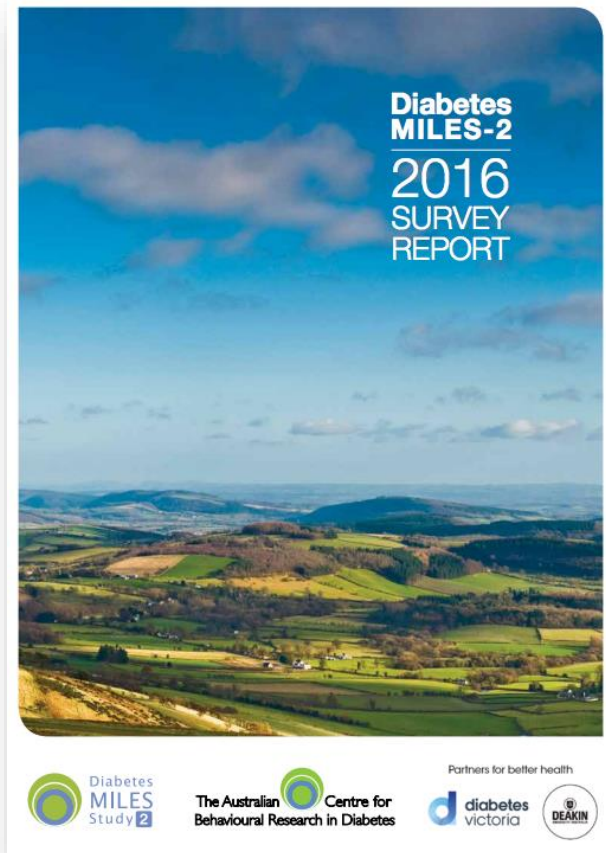
## Management and Impact for Long-term Empowerment & Success



- International collaborative
  - Large-scale, national surveys of people with diabetes
  - Using validated measures and novel measures in development
- Key topic areas:
  - **Psychological**: depression, anxiety, distress
  - **Behavioural**: self-management
  - **Social**: health care, social and peer support
- Australian surveys to date:
  - 2011: >3000 T1D or T2D adults
  - 2014: >700 T1D adolescents & their parents
  - 2016: >2000 T1D or T2D adults incl. longitudinal sample ~500

[www.diabetesMILES.org](http://www.diabetesMILES.org)

# Diabetes MILES-2



- National **online** survey focused on psychosocial aspects of diabetes
  - Questions tailored to diabetes type / treatment
- Eligibility:
  - Adults (18-75)
  - Self-reported diagnosis of T1D or T2D
  - able to read/write in English
- Advertised nationally & invitation sent to:
  - 20,000 Australians registered with diabetes
  - 2011 MILES study cohort (~2000)
- Final Sample: N = 2,342
  - 1078 T1D: 59% women; aged 44±15yrs
  - 1263 T2D: 43% women; aged 61±9yrs; 42% insulin-treated
  - 504 longitudinal cohort
- Details: Browne et al. BMJ Open, 2017:7, 2

[www.diabetesMILES.org](http://www.diabetesMILES.org)

# Findings from Diabetes MILES-2



- 1. Diabetes distress
- 2. Diabetes stigma
- 3. Self-compassion

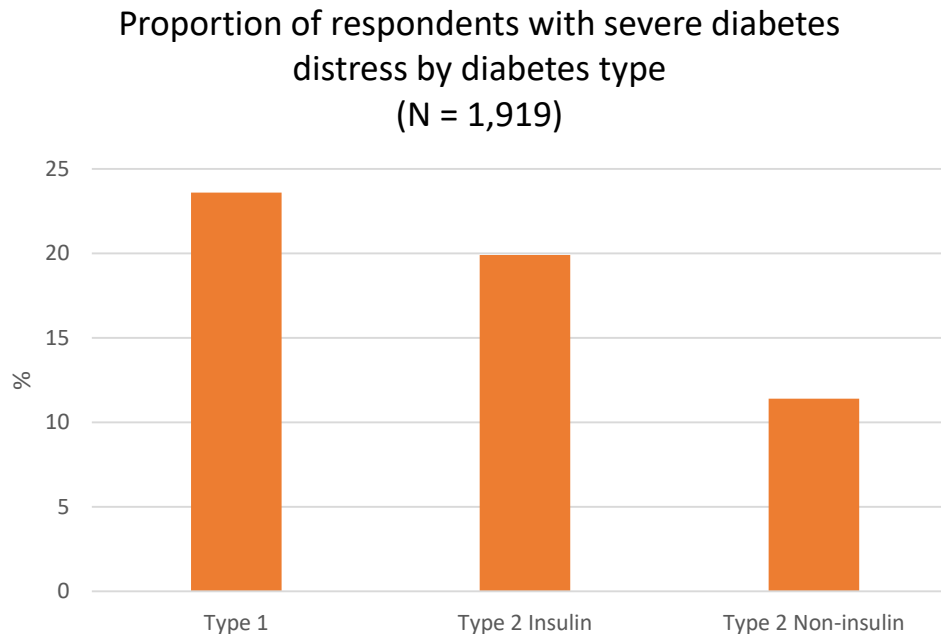


# Diabetes distress

- Negative emotional responses to living with diabetes...
  - the diagnosis of diabetes
  - threat of complications
  - self-management demands
  - unresponsive HCPs and/or
  - unsupportive interpersonal relationships
- Part of the “spectrum of experience of diabetes”
  - When severe, a problem that needs to be addressed
- Measured by Problem Areas In Diabetes (PAID) scale

# Severe diabetes distress

- Those with T1D more likely than others to experience *severe* diabetes distress
  - 40 cut-off score



# Top 5 problem areas causing distress



## Type 1 diabetes

1. Worrying about the future and the possibility of serious complications
2. Feelings of guilt or anxiety when you get off track with your diabetes management
3. Feeling 'burned-out' by the constant effort needed to manage diabetes
4. Worrying about low blood sugar reactions
5. Not knowing if your mood or feelings are related to your diabetes

## Type 2 diabetes

1. Worrying about the future and the possibility of serious complications
2. Feelings of guilt or anxiety when you get off track with your diabetes management
3. Not knowing if your mood or feelings are related to your diabetes
4. Feeling constantly concerned about food and eating
5. Feeling 'burned-out' by the constant effort needed to manage diabetes

“It’s a scary thing – always hearing about how diabetes can cause serious complications – HPs just throw these things out there to scare you into looking after yourself better, but instead it just makes you want to go more into denial about it”

- Woman with T1D, aged 20





# Diabetes stigma

- Exclusion
- Rejection
- Blame
- Stereotyping
- Status loss
- ...that results from a negative social judgement about diabetes
- ...perceived or experienced first-hand

## BMJ Open 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes

Jessica L Browne,<sup>1,2</sup> Adriana Ventura,<sup>1,3</sup> Kylie Mosely,<sup>4</sup> Jane Speight<sup>1,2,5</sup>

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Browne JL, Ventura A, Mosely K, et al. *BMJ Open*

### ABSTRACT

**Objectives:** While health-related stigma has been the subject of considerable research in other conditions (obesity and HIV/AIDS), it has not received substantial attention in diabetes. The aim of the current study was to explore the social experiences of Australian adults living with type 2 diabetes mellitus (T2DM), with a particular focus on the perception and experience of diabetes-related stigma.

**Design:** A qualitative study using semistructured interviews, which were audio recorded, transcribed and subject to thematic analysis.

### Setting:

This study was conducted in metropolitan areas of Victoria, Australia.

### Participants:

Adults aged ≥18 years with T2DM living in Victoria were eligible to take part. Participants were recruited primarily through the state consumer organisation representing people with diabetes. A total of 27 adults with T2DM took part: 15 (56%) were women; median (IQR) age was 42 (23) years and diabetes duration was 15 (20) years.

### Results:

Australian adults with T2DM perceive and experience T2DM-specific stigma as well as stigma-by-association with type 2 diabetes. Such stigma is characterised by blame, negative social judgement, stereotyping, exclusion, rejection and discrimination. Participants identified the media, family and friends, healthcare professionals and school teachers as sources of stigma. The negative consequences of this stigma span numerous life domains, including impact on relationships and social identity, emotional well-being and behavioural management of T2DM. This stigma also led to reluctance to disclose the condition in various environments. Adults with T2DM can be both the target and the source of diabetes-related stigma.

### Conclusions:

Stigmatisation is part of the social experience of living with T2DM for Australian adults. Strategies and interventions to address and mitigate this diabetes-related stigma need to be developed and evaluated.

### Strengths and limitations of this study

- This qualitative study is the first to describe, in detail, the perceptions and experiences of diabetes-related stigma from the perspective of adults with type 2 diabetes mellitus (T2DM).
- While the small sample size may limit the representativeness of the findings, efforts were made to include a broad cross-section of adults with T2DM and data saturation was achieved.

## BMJ Open 'I'm not a druggie, I'm just a diabetic': a qualitative study of stigma from the perspective of adults with type 1 diabetes

Jessica L Browne,<sup>1,2</sup> Adriana Ventura,<sup>1,3</sup> Kylie Mosely,<sup>4</sup> Jane Speight<sup>1,2,5</sup>

**To cite:** Browne JL, Ventura A, Mosely K, et al. 'I'm not a druggie, I'm just a diabetic': a qualitative study of stigma from the perspective of adults with type 1 diabetes. *BMJ Open* 2014;4:e005625. doi:10.1136/bmjopen-2014-005625

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Browne JL, Ventura A, Mosely K, et al. *BMJ Open*

### ABSTRACT

**Objectives:** While health-related stigma has been the subject of considerable research in other conditions (eg, HIV/AIDS, obesity), it has not received substantial attention in diabetes. Our aim was to explore perceptions and experiences of diabetes-related stigma from the perspective of adults with type 1 diabetes mellitus (T1DM).

**Design:** A qualitative study using semistructured interviews, which were audio recorded, transcribed and subject to thematic analysis.

**Setting:** All interviews were conducted in non-clinical settings in metropolitan areas of Victoria, Australia.

**Participants:** Adults aged ≥18 years with T1DM living in Victoria were eligible to take part. Participants were recruited primarily through the state consumer organisation representing people with diabetes. A total of 27 adults with T1DM took part: 15 (56%) were women; median (IQR) age was 42 (23) years and diabetes duration was 15 (20) years.

**Results:** Australian adults with T1DM perceive and experience T1DM-specific stigma as well as stigma-by-association with type 2 diabetes. Such stigma is characterised by blame, negative social judgement, stereotyping, exclusion, rejection and discrimination. Participants identified the media, family and friends, healthcare professionals and school teachers as sources of stigma. The negative consequences of this stigma span numerous life domains, including impact on relationships and social identity, emotional well-being and behavioural management of T1DM. This stigma also led to reluctance to disclose the condition in various environments. Adults with T1DM can be both the target and the source of diabetes-related stigma.

**Conclusions:** Stigmatisation is part of the social experience of living with T1DM for Australian adults. Strategies and interventions to address and mitigate this diabetes-related stigma need to be developed and evaluated.

### INTRODUCTION

Health-related stigma is the negative social judgement based on a feature of a condition or its management that leads to perceived or

### Strengths and limitations of this study

- To our knowledge, this study is the first to conduct a systematic and in-depth examination of the perception and experience of diabetes-related stigma from the perspective of adults with type 1 diabetes mellitus.
- Strengths of this study include the novelty of the topic of enquiry, and the richness of data collected through in-depth interviewing.
- Limitations of this study include the fact that people born outside Australia and those living in rural/regional areas were under-represented in our sample.

experienced exclusion, rejection, blame, stereotyping and/or status loss.<sup>1,2</sup> This is a destructive social phenomenon; one that has been observed and studied extensively in conditions such as HIV/AIDS,<sup>3–5</sup> obesity,<sup>6,7</sup> and mental illness.<sup>8–14</sup> Type 1 diabetes mellitus (T1DM) is a serious chronic condition that requires unrelenting self-management (including multiple daily insulin injections or insulin pump therapy), and can impact on both quantity and quality of life. Traditionally, T1DM research has focused on the biomedical aspects of aetiology and management of the condition. However, recent decades have witnessed the rise of psychosocial research, exploring the emotional, behavioural and social aspects of living with T1DM.<sup>15</sup>

There is limited but growing awareness that people with diabetes face stigmatisation and discrimination as a result of their condition. The International Diabetes Federation has identified diabetes-related stigma as a problem that needs urgent attention, and one of the organisation's key priorities is to 'champion a world free from discrimination and stigma for people with diabetes' (ref. 16, p.10). A recent large-scale multinational

# Measuring diabetes stigma

- **Newly developed:** Type 1 and Type 2 Diabetes Stigma Assessment Scales (DSAS-1 and DSAS-2)
  - 19 items each
  - DSAS-1 subscales:
    - Treated differently
    - Blame and judgement
    - Identity concerns
  - DSAS-2 subscales:
    - Treated differently
    - Blame and judgement
    - Self-stigma
- **Enables quantitative assessment of the relationships with diabetes outcomes**
  - E.g. diabetes distress, HbA1c



# Top 3 endorsed stigma items

## Type 1 diabetes

1. Because I have type 1 diabetes, some people judge me if I eat sugary food or drinks (e.g. cakes, lollies, soft drink)
2. Some people make unfair assumptions about what I can and cannot do because of my type 1 diabetes
3. Some people assume that it is my fault I have type 1 diabetes (e.g. I ate too much sugar, I could have prevented it)

## Type 2 diabetes

1. Because I have type 2 diabetes, some people assume I must be overweight, or have been in the past
2. There is a negative stigma about type 2 diabetes being a 'lifestyle disease'
3. Because I have type 2 diabetes, some people judge me for my food choices

“As if the disease weren’t bad enough, the stigma of type 2 diabetes is worse”

- Man with T2D, aged 53



# Diabetes stigma x diabetes distress



- Significant, positive association between diabetes stigma and diabetes distress, by diabetes type and treatment

Characteristic	Type 1	Type 2
Female	✓	✓
Diabetes complications	✓	✓
Younger age <35 years	✓	✓
Less years lived with diabetes	✓	
Not in a relationship	✓	
Using insulin therapy		✓

**Note: unpublished findings: please do not circulate more broadly.**

# Self-compassion



- The practice of being kind, gentle, supportive and understanding toward oneself
  - Particularly when faced with difficult life struggles (Neff, 2003)
- It promotes an attitude of acceptance that imperfection is part of shared human experience
  - Frustrations, losses, mistakes, ‘failures’ - part of the human condition

# Self-compassion

## What it is

- Self-kindness
  - Warm and understanding toward oneself

“Managing my diabetes is not always easy but I am doing the best I can”

## What it is not

- Self-judgement
  - Self-criticism
  - Harsh judgement

“Managing diabetes shouldn’t be this hard - I am such a failure”

# Self-compassion

## What it is

- Mindfulness
  - Non-judgement
  - Observe thoughts and feelings as they are



## What it is not

- Over-identification
  - Caught-up in thoughts and feelings
  - Negative reactivity





# Self-compassion

## What it is

- **Common humanity**
  - Recognising that all humans suffer, fail, make mistakes, are imperfect!

“A lot of people with diabetes feel the way I do from time-to-time”

## What it is not

- **Isolation**
  - Feeling as though you are the only one feeling this way

“No one else finds diabetes this hard to manage, why is it so hard for me?”

# Self-compassion in the broader literature



- **Greater self-compassion associated with:**
  - Emotional resilience/well-being (MacBeth & Gumley, 2012)
  - Ability to self sooth (physiological process) (Porges, 2007)
  - Health promoting behaviours (e.g. healthy eating and physical activity) (Sirois et al, 2014)
  - Less self-stigma in overweight and obesity (Hilbert et al, 2015)

# Self-compassion and diabetes



- **Greater self-compassion associated with:**
  - Better well-being, more optimal HbA1c, higher engagement with healthy diet and physical activity (Ferrari et al., 2017)
  - Lower diabetes distress and depression, and acts as a buffer between high distress and sub-optimal HbA1c (Friis et al., 2015)

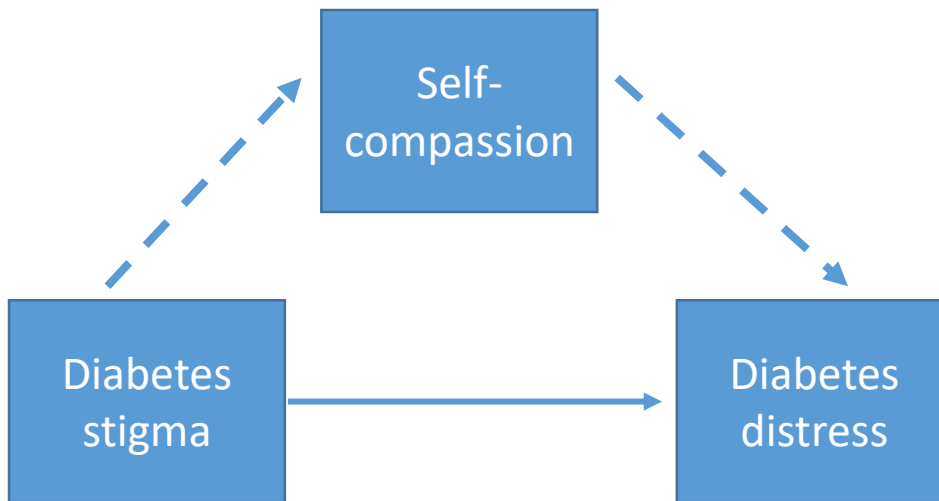
# Self-compassion and diabetes outcomes



- **Self-compassion significantly associated with:**
  - Behavioural: **more optimal diet and physical activity**
  - Clinical: **more optimal HbA1c**
  - Emotional: **less depression, anxiety, diabetes distress**
  - Social: **less diabetes stigma**

**Note: unpublished findings: please do not circulate more broadly.**

# Effect of self-compassion on diabetes stigma and distress

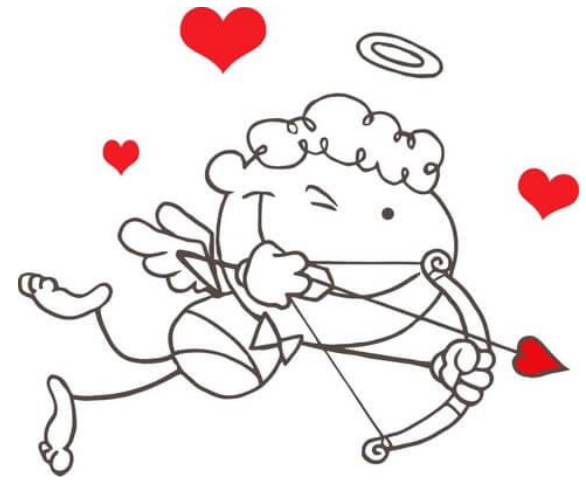


When self-compassion is LOW and stigma is HIGH = HIGHER diabetes distress

When self-compassion is HIGH and stigma is LOW = LOWER diabetes distress

**Note: unpublished findings: please do not circulate more broadly.**

# How to kill two birds with one stone?



- Kill them with kindness, I say.
  - Self-compassion is a relevant construct in relation to diabetes
- Increasing self-compassion is a good option, and you don't need to be a psychologist to do it!
  - Offering strategies for coping with diabetes and changes to diabetes management is crucial

# Self-compassion in practice

“The best way to counteract self-criticism is to understand it, have compassion for it, and then replace it with a kinder response”

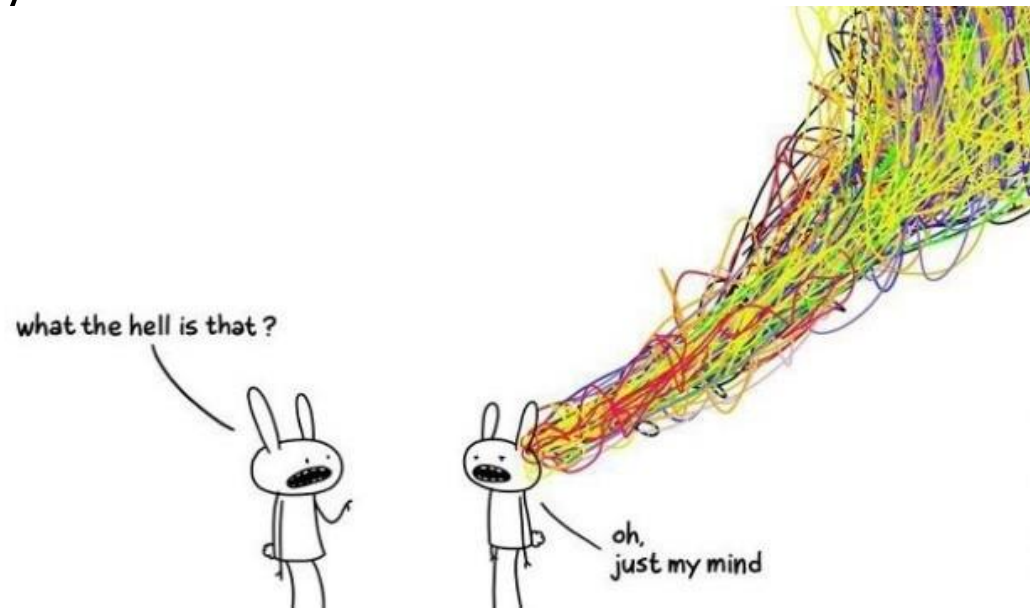
– Kristin Neff

- What can you do?
  - Every consultation is an opportunity to focus on the emotional well-being of the person ...



# What YOU can do

- Be *mindful* of your communication with the person with diabetes
  - Notice when they use overly critical language about their diabetes or themselves
  - Notice when you use judgemental or critical language about their diabetes
    - Even when you don't say it aloud!





# Self-compassion exercise

- **How would you treat a friend?** (for the person with diabetes)
  - Ask them to think about times when a friend has felt really badly about themselves and how they typically respond
  - Ask them to think about when they have felt really badly about themselves and how they typically respond
    - Compare the differences and explore why!
  - *Encourage them to treat themselves like they would a good friend!*

# What YOU can do

- *Be honest with the person, but always kind*
  - Remind them that being imperfect and experiencing difficulties is inevitable and part of being human.
  - Work out a realistic plan for moving forward together.
  - You might like to use the phrase:  
*“You’re doing the best you can right now”* (if this is true!)



# What YOU can do

- Tell them they are not alone
  - Help the person to recognise that other people with diabetes feel similarly to them at times (e.g. like a failure)
  - Use the phrase: “*You are not alone*”
  - Peer support is an option

**ndss**  
national diabetes services scheme

**diabetes australia**

## Peer support for diabetes

Peer support is a way for you to connect with people who also face the daily challenges of managing diabetes. Sharing your experiences with other people who have diabetes can help you feel less alone. Read on to find out about peer support and how to access it in your area.

**What is peer support?**

Peer support is when people living with a chronic condition (like diabetes) give and/or receive support from one another.

Many people who have diabetes have never talked to anyone else with diabetes, even though they may want to. This can feel very isolating.

People with diabetes may access peer support because:

- family and friends, despite their best efforts, can't fully understand what it's like to live with diabetes
- health professionals may not always have the time to talk about all aspects of living with diabetes.

Peer support is a way for people with diabetes to share their:

- knowledge and skills
- insights and experiences
- thoughts and concerns
- feelings about living with diabetes.

This can happen in the form of organised face-to-face peer support groups or one-to-one telephone support, casual conversation, or through various technologies such as SMS texts and the internet (eg Facebook, Twitter, email, online forums).



*"It's nice to be able to contact someone who is exactly the same as you. They give you that little bit of encouragement. You may be having a flat day and you just want to go, 'Oh, I don't want to get up for work', and that someone is saying, 'No, you can do it' ... I think it's great."*

James, 26, person with diabetes

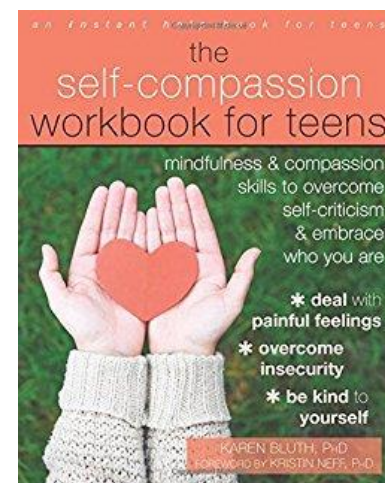
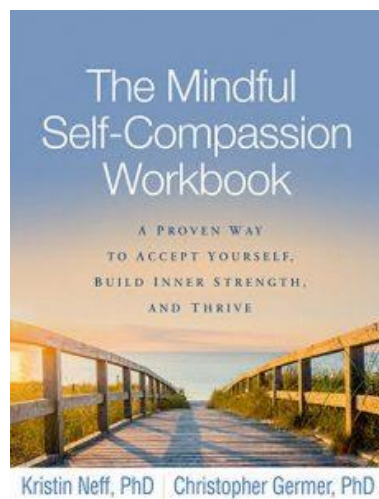
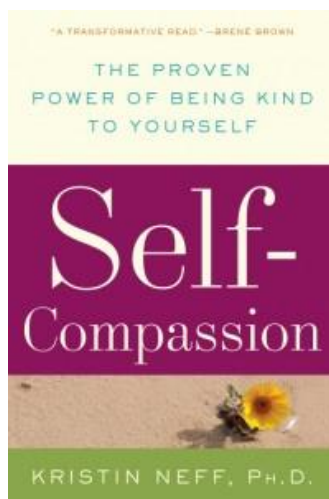
**Helpline 1300 136 588** **ndss.com.au**

The National Diabetes Services Scheme is an initiative of the Australian Government administered with the assistance of Diabetes Australia.

1 of 9

# Resources

- Simple exercises can be implemented by YOU
- Readings, exercises, tools (including questionnaires) and professional courses
  - [www.selfcompassion.org](http://www.selfcompassion.org)



# Your health matters too

Contents lists available at ScienceDirect



International Journal of Nursing Studies

journal homepage: [www.elsevier.com/ijns](http://www.elsevier.com/ijns)



## Relationships between nurses' empathy, self-compassion and dimensions of professional quality of life: A cross-sectional study



Joana Duarte<sup>a</sup>, José Pinto-Gouveia, Bárbara Cruz

Cognitive-Behavioral Res


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Nurse Education Today

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## A pilot study exploring the relationship between self-compassion, self-judgement, self-kindness, compassion, professional quality of life and wellbeing among UK community nurses

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Compassion fatigue  
District nurses  
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Self-compassion  
Wellbeing


### ABSTRACT

**Background:** Compassion fatigue and bu  
relationship between self-compassion, s  
and wellbeing among community nurses  
**Aim:** To measure associations between  
community nurses.

**Method:** Quantitative data were collecte  
Quality of Life Scale; (2) Self-Compassion  
passion For Others Scale, used to measure  
and burnout.

**Participants:** A cross sectional sample of  
diploma at a University in the North of E  
**Results:** Results show that community nur  
report less burnout. Greater compassion  
and wellbeing, whilst also being negativ  
**Conclusion:** High levels of self-compassio  
nity nurses have greater compassion; s  
wellbeing, and less burnout. The implica  
greater compassion.

Contents lists available at ScienceDirect



International Journal of Nursing Studies

journal homepage: [www.elsevier.com/ijns](http://www.elsevier.com/ijns)

### Guest Editorial

## On self-compassion and self-care in nursing: Selfish or essential for compassionate care?



Keywords:  
Caring  
Compassion  
Nurse  
Nursing  
Self-care  
Self-compassion

Compassionate care in nursing is increasingly an international concern. While the literature to date has focussed on redressing a compassion and care deficit across the nursing discipline (Crawford et al., 2014; Dewar et al., 2014; Scott, 2014), we suggest here that due consideration be given to its relationship to self-care and self-compassion in nurses. After all, a deficit in these compromises nurses' therapeutic use of self in the provision of compassionate care to patients. As a noted scholar and practitioner of compassion, the Dalai Lama (2003, p. 125) argues that:

For someone to develop genuine compassion towards others, first he or she must have a basic upon which to

## Health Practitioners and the Directive Towards Compassionate Healthcare in the UK: Exploring the Need to Educate Health Practitioners on How to be Self-Compassionate and Mindful Alongside Mandating Compassion Towards Patients

Helen Egan<sup>\*</sup>, Michail Mantzios, Craig Jackson

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## Compassion and self-compassion in medicine: Self-care for the caregiver

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1. Faculty of Nursing and Midwifery, The University of Sydney  
2. ANU Medical School, Australian National University

### Abstract

Concerns increase in implications suggests how for greater ci benefits for compassiona © 2016 King

### EDITORIAL

In the words of the 14<sup>th</sup> Dalai Lama, an esteemed scholar of compassion:

*For someone to develop genuine compassion towards others, first he or she must have a basis upon which to cultivate compassion, and that basis is the ability to connect to one's own feelings and to care for one's own welfare. . . Caring for others requires caring for oneself.<sup>6</sup>*

### importance of self-care

It is not unique to medicine, doctors working in this profession appear at risk of stress and burnout. From doctors' personal stressors, exposure to patients' pain and suffering is a normal feature of clinical practice.<sup>7,8</sup> Traditionally, many doctors have worn the badge of 'burnout' as a badge of honour.<sup>9</sup> But many argue that the impact of stress can compromise the compassionate care provided to patients in addition to its effect on the doctor's well-being.<sup>8-10</sup> Unfortunately there is evidence to suggest that anxiety and depression are common, and the prevalence of burnout in doctors has been found to be higher than in the general population.<sup>5</sup>



# Is self-compassion the antidote to diabetes stigma and distress?

- This is a novel area of research
- Clearly an important construct for diabetes with promising evidence to suggest that a focus on SC will improve diabetes outcomes
- BUT more work is needed to examine effectiveness of Mindful Self-Compassion (MSC) intervention among people with diabetes
- **ANSWER: wait and see**

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Thank you

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