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# iDEAL Group Position Statement

# Promotion of emotional and psychological well-being for people living with diabetes – A Call to Action

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The iDEAL (Insights for Diabetes Excellence, Access and Learning) Group exists to enable the delivery of best practice in diabetes care for every person living with diabetes (PLwD). We are a highly engaged independent multidisciplinary team of representative experts with a visionary outlook to improve diabetes care outcomes across the UK.

The group includes the perspective of people living with diabetes, clinical service provider organisations and their professional bodies as well as the main charities and interest groups. This enables networking and outreach to gather, evaluate and share evidence to reach practitioners delivering diabetes care and those in need of it. We lobby policymakers and challenge perceptions to encourage the redirection of resources and influence education and training opportunities to meet the needs of all individuals living with diabetes.

Our programme of action is focused on harnessing our professional expertise to build consensus, network, research, share knowledge and collectively seek to make things better; both for practitioners working in partnership with and for people living with diabetes.

Emotional health is how we think and feel – it's about a sense of well-being – our ability to cope with life events and how we acknowledge our own emotions as well as those of others. It doesn't mean being happy all the time (Samaritans 2020).

#### **KEY MESSAGES**

- An integrated approach that gives equal weight (value) to psychological well-being and biomedical outcomes is essential to diabetes care.
- Raising and acknowledging the emotional demands of living with diabetes and engaging in a non judgemental open conversation is often enough for people to feel supported.
- A positive rapport and therapeutic relationship is key to ensuring there is a safe space to explore and support people in this way.
- Systematic screening is recommended and there are measures available to identify issues however, there are many barriers to their employment by health care professionals (HCPs).
- It is good practice to assess or screen for difficulties at particular points in time such as at diagnosis, life transitions, the onset of complications and when there are significant changes in treatment.
- There are many resources to support both the PLwD and the HCP (e.g. web, social prescribing, peer support, community resources).
- Both system and organisational change is required to facilitate the transformation in the way practice is delivered to enable greater emphasis on emotional and psychological support in diabetes care.
- There are many tools available to assist clinicians they can be found in the Appendix (Practitioner and Service Development Resource Guide).



#### **INTRODUCTION**

This iDEAL position statement acknowledges the plethora of high quality reviews and it would be beyond the scope of this paper to synthesise this evidence base. By highlighting key messages and signposting to resources, we aim to support timely intervention by HCPs working with PLwD, particularly in the primary care setting.

The higher prevalence rates of psychological difficulties for PLwD, are well established, these include low mood, major depressive disorder, anxiety, disordered eating and diabetes distress. Studies suggest an elevated risk of experiencing depression equivalent to people with other long term health conditions (10-12%) and double that of the general population (5%) (Anderson et al, 2001, 2008, Lloyd et al, 2000, de Groot et al, 2016). Anxiety in PLwD is less well researched but studies suggest prevalence rates of 15-25% (Lloyd, 2000), and even up to 49% (Peyrot and Rubin, 1997). However, accurate reporting of prevalence rates vary because they are confounded by the method of collection (self report versus interview) and mislabelling the diagnosis (i.e. diabetes distress being labelled as depression) (Skinner et al, 2019, Fisher et al, 2019).

The risk of experiencing disordered eating behaviours is increased for people living with both type 1 and type 2 diabetes compared with their peers (Broadley et al, 2020). The evidence within this area is limited but growing. It is increasingly evident there are an array of disordered eating behaviours without categorisation in this area, resulting in a number of PLwD remaining unsupported because they do not neatly fit the diagnostic criteria for eating disorders (Broadley et al, 2020). iDEAL welcomes the current research into identifying these as a step in supporting the development of screening tools and individualised treatment approaches (Odiase et al, 2020, Phillips et al, 2020, Beckwith et al, 2020).

In addition to the psychological difficulties detailed above, over the last 25 years, there has been the development of a construct known as 'diabetes distress' which sought to further understand and describe the emotional burden of living with a long term condition that requires constant attention and concomitant threat. This construct has acted as a catalyst for the emotional and psychological well-being of PLwD to be given equal status as the biomedical components of diabetes. There are several reviews (Skinner et al, 2019, Fisher et al, 2019) that indicate how best to support PLwD specifically with respect to diabetes distress and toolkits and resources these will be further explored below.

The social milieu within which people with diabetes currently live is also of great importance. There is a culture of blame and judgement around conditions that are viewed to be as a direct result of the person's behaviour. People living with type 2 diabetes find themselves blamed and stigmatised by the media as being responsible for their condition through lifestyle choices with little recognition of the potential risk factors and the obesogenic environment in which individuals find themselves. This has added further to the distress experienced for those PLwD who often have to endure misconceptions and judgement from others which can be internalised by the PLwD and prevent them seeking the help and support they need. These attitudes may also pervade their healthcare and their relationships with HCPs (please see Odiase et al, 2020, Phillips et al, 2020) and potentially even influence policy measures (Mata & Hertwig, 2018).

Finally, resources are limited. Although the political context might possibly be about to change with respect to funding decisions, the NHS has been chronically underfunded and this has had an impact on the resources available for both physical and mental health. There is a pressure on time, in busy clinics and long waiting times to see specialist mental health practitioners. These act as barriers to engaging in conversations about psychological well-being, as well as many HCPs, feeling they have had insufficient training and do not have the ongoing support to engage in consultations that include a focus on the emotional impact of living with diabetes.

However, despite these challenges, there are grounds for optimism as the growing zeitgeist is that the psychological and emotional aspects of living with long term conditions like diabetes must be acknowledged and supported in everyday clinical settings.

This paper, therefore, is a 'call to action' to move beyond acknowledging that there is an issue to be addressed towards arguing and making some real change in the design and delivery of our services so that psychological and emotional well-being is given equal precedence to biomedical makers. Despite the vast evidence base that there is an issue limited resources are given to this area, the gap has been highlighted in Too Often Missing (Diabetes UK, 2019a). iDEAL supports the recommendations from Diabetes UK's report and the main themes are summarised in Table 1.



#### **TABLE 1: MAIN RECOMMENDATIONS FROM 'TOO OFTEN MISSING'**

Aim or focus	Recommendation	
The psychological and emotional aspects of living with diabetes to be acknowledged in all diabetes care via systematic care and support planning.	<ul> <li>Engage commissioning and integrated care systems.</li> <li>Development and use current resources to support conversations around psychological well-being in consultations.</li> <li>Ensure that physical and mental health outcomes are recorded.</li> <li>Ensure these issues are included in NICE guidance.</li> <li>To be included in all self management education programmes.</li> </ul>	
To ensure links with the third sectors to ensure that peer support, community groups, self help resources are offered as options.	<ul> <li>Increase access to social prescribing.</li> <li>Commission peer support services.</li> <li>Increase awareness of services and signpost accordingly.</li> </ul>	
Diabetes services to be supported by specialist mental health professionals (eg Psychologists, Liaison Psychiatrists).	<ul> <li>Commissioners to ensure an integrated mental health professional with knowledge of diabetes.</li> <li>Ensure IAPT LTC services are available.</li> <li>Ensure liaison between IAPT and the diabetes services.</li> </ul>	
Develop an integrated pathway for diabetes and emotional and psychological well-being.	In progress.	
Training for all HCPs working in diabetes in this area.	Links with Health Education England, academic institutions and commissioners.	
For mental health professionals providing care for PLwD to have training in diabetes.	IAPT, commissioners and other mental health professionals.	

This position paper aims to cover three key areas; the specifics of supporting emotional and psychological well-being for PLwD, the ethos of a service that aims to work in this way and the organisational and supportive systems that are required.

### 1. Supporting emotional and psychological well-being for people living with diabetes

#### 1.1 Prevention of psychological difficulties

As with any other aspect of our health our emotional and psychological wellbeing requires ongoing management. This requires a fundamental societal and cultural shift. Although our physical wellbeing is based on numerous factors such as genetics and environment it is well established that our own actions have a role to play and that maintenance of health requires engagement in lifestyle behaviours. Prevention of psychological difficulties is based on this same premise that if a person becomes more informed about the factors that may support their emotional wellbeing they may avert difficulties or seek help at a sooner point. Psychoeducation is fundamental to this approach as it allows the person to gain an understanding of the factors that may influence their psychological wellbeing and can enable people to make a more informed choice about how they would like to proceed in just the same way as any other aspect of self management education. Increased awareness of the emotional and psychological impact of diabetes is crucial as it normalises the perfectly understandable responses that a PLwD may find distressing or concerning without this information. One example is the common or expected reactions people experience following a diagnosis of diabetes (please also see Odiase et al,



2020, Phillips et al, 2020). Being aware that it can be similar to a bereavement and can include shock, disbelief, avoidance, sadness and anger. This potentially facilitates the person to engage in conversations they may have otherwise avoided due to concerns about 'not coping' or being judged.

An increased insight that strong emotions can occur not only at diagnosis but at other critical times when the impact of living with diabetes re-emerges such as being asked to pay extra for holiday insurance, the additional preparation and planning required when trying for a pregnancy, changes of treatment or experiencing a complication of diabetes can support the person to view these experiences as normal and trigger them to seek out additional help if required.

It is therefore imperative that information about the psychological impact of living with diabetes is provided as a standard in structured self-management education (SME). It can include what is to be expected in terms of psychological adjustment to diabetes, but also introduce the concept of diabetes distress and encourage individuals to seek assistance with issues around mood, anxiety, eating or emotional factors that are getting in the way of managing their diabetes. This approach can be further enhanced by conversations around emotional wellbeing part of routine clinical appointments and could be integrated into a collaborative care planning process (Odiase et al, 2020, Phillips et al, 2020).

The inclusion of screening measures could further reinforce the importance of psychological well-being and there are a number of advocates that argue psychological indicators are given equal parity to biomedical outcomes in routine clinical settings as part of a holistic assessment (Young-Hyman et al, 2016). There are useful examples of screening that can be employed in routine practice. In primary care settings in the UK short screening questions used to highlight issues with low mood had been utilized followed by standardised measures such as the Patient Health Questionnaire-9 (PHQ9). There are excellent examples of the process in diabetes services (Health innovation Network and Kings Health Partners, 2017). Recent reviews (Fisher et al 2019, Skinner et al, 2019) suggest that the Problem Areas in Diabetes Scale (PAID) is probably the screening tool of choice as it provides an overview of the many factors contributing to diabetes distress and can be used with people living with type 1 and type 2 diabetes. There are however measures that have been specifically developed for people living with Type 1 Diabetes (T1- Diabetes Distress Scale) and Type 2 (Diabetes Distress Scale) if the person would benefit from a more detailed review of the issues particular to managing their diabetes. There is also a short item measure with 2 items (DDS2). The interested reader is signposted to two reviews by Fisher et al, (2019) and Skinner et al, (2019).

As highlighted above PLwD can experience stigma as a result of their condition. The specific themes that have been reported are feeling blamed by others for causing their condition, experiencing negative stereotyping, having a sense that they are discriminated against and have their opportunities limited by their diabetes (Browne et al, 2013). The sources of stigma appear to be the media, friends, family, colleagues and in their interactions with some HCPs. The experience or fear of stigma can impact both people's psychological and physical wellbeing. The suggested mechanism is that fear of stigma can result in concealment attempts such as avoiding monitoring or injecting insulin in public, not telling family, friends or colleagues which can lead to not engaging in self-management behaviours. It may influence diabetes distress if the person perceives themselves to be to blame for the condition or in some way different. There are links to obesity for people living with type 2 diabetes and the fears of negative attitudes towards injections and needles for those with type 1 and 2 diabetes (Schabert et al, 2013).

Given the profound impact stigma can have on the PLwD it is crucial that consultations are conducted with the ethos of non-judgement and unconditional positive regard in accordance with the core conditions of any person centred approach (Rogers, 1951). This supports the development of a positive rapport and promotes honesty and engagement. The language employed has been found to be important to a person's experience of healthcare and how they feel about the condition. Language Matters (2018) is a useful summary document that has been developed and champions the positive principles of collaboration, non-judgement, empathy and the powerful impact of language that implies blame. Of course, this approach should be employed across all consultations including those where emotional and psychological well-being is explored.

Finally, it may also be of benefit to include in any psychoeducation approach a discussion about stigma and how the person may want to tackle or address this in their life in a way averts the negative consequences that can occur such as concealment or negative emotional responses.



#### 1.2 Early intervention

Many of the approaches that support prevention as presented above are also applicable to helping the person to recognise as early as possible if living with diabetes is having a negative impact on their psychological wellbeing and when to seek help. Once again information gained about common emotional and psychological reactions is of help. If psychoeducation is a core component of all self-management education approaches these issues will have already been raised. Written information and/or signposting to web based resources about when to seek advice or assistance can act as a reference source for both the PLwD and other people in their life (Table 2).

Screening routinely and at significant times should also be considered to highlight issues at an earlier point as people can be reluctant to raise the subject of psychological difficulties in a clinic situation. Screening tools or consultation prompts that include emotional and psychological issues as part of the menu to be discussed can enable the PLwD to raise the subject. It can help to promote the benefits of early intervention in the same way that we would with any physical issue in order to reduce the barriers to disclosing or describing difficulties in a consultation (Fisher et al, 2019) (Table 2).

With respect to specific interventions, there is the pyramid model of care that classifies psychological distress in terms of the levels of care required to help with a particular difficulty (Figure 1). This model has been widely used in mental health services and adapted for use in diabetes care. It recognises that all HCPs working in diabetes are responsible for ensuring some element of psychological care (Diabetes UK, 2010). This model suggests that at the bottom of the pyramid PLwD can be well supported by HCPs working in primary and specialist care who ideally will have had additional training and support. As an individual's difficulties become more complex they may require more specialist intervention from mental health care professionals such as clinical psychologists and psychiatrists.



#### **LEVEL** 5

Severe and complex mental illness, requiring specialist psychiatric intervention(s).

#### **LEVEL 4**

More severe psychological problems that are diagnosable and require biological treatments, medication and specialist psychological interventions.

#### **LEVEL 3**

Psychological problems which are diagnosable or classified but can be treated solely through psychological interventions. This includes mild and some moderate cases of depression, anxiety states and obsessive compulsive disorders.

#### **LEVEL 2**

More severe difficulties with coping, causing significant anxiety or lowered mood, with impaired ability to care for self as a result.

#### LEVEL 1

General difficulties coping with diabetes and the perceived consequences of this the person's lifestyle etc. Problems at a level common to many or most people receiving the diagnosis.



## **TABLE 2: EARLY INTERVENTION**

Aim or focus	Examples of intervention	НСР
To provide support and information at diagnosis and other key points.	Psycho education i.e. information and discussions about the common emotional responses that PLwD experience and how to access support if required. Ensure it is embedded in SME and provide written resources and links to online support such as Diabetes UK.	All members of the healthcare team with assistance/guidance from a psychologist/mental health practitioner embedded in a team or with knowledge and experience of working with PLwD.
Provide interventions that promote well-being.	Mindfulness, compassionate mind based approaches, acceptance and commitment therapy, resilience interventions and social prescribing.	Practitioners with training in the relevant interventions.
Support people experiencing diabetes distress.	Embed in standard SME. Provide specific diabetes distress interventions. See chapter in Diabetes and Emotional Health Practical guide (Diabetes UK, 2019b).	All HCPs – with additional training and support.
Identify and support those with mild/ moderate low mood.	<ul> <li>Screening or assessment for difficulties with mood. Menu of options discussed including Improving access to Psychological Therapy (IAPT).</li> <li>Self Help Materials (see appendix).</li> <li>Web based interventions such as Silver Cloud or Big White Wall.</li> <li>DUK resources such as Information Prescriptions.</li> <li>Diabetes and Emotional Health – Practical guide which includes recommendations about when to refer on for more complex difficulties. (Diabetes UK, 2019b).</li> </ul>	All HCPs. Specific interventions provided by HCPs trained in low intensity CBT.
Identify, and support people around disordered eating.	Psychoeducation around the impact of diabetes on eating. Information can be found on the website Diabetics with Eating disorders. The Centre for Clinical interventions and the Diabetes Emotional Health Practical Guide (see Appendix).	All HCPs to ask about these issues and discuss. Specific screening tools can be used (Broadley et al, 2020).  Also to refer on to specialist eating disorder services when required and work closely with specialist eating disorder services.



#### 1.3 Specialist intervention

It is beyond the scope of this document to determine or describe in any detail the services that should ideally be available to PLwD who require specialist services. There are some specific recommendations that iDEAL would endorse as described in other guidelines (Diabetes UK, 2019, London Strategic Clinical Network, 2014). It has been noted in many service user consultations that PLwD prefer to receive their mental health care from services that have some knowledge of diabetes and the tasks involved in its day to day management. This is a challenge for clinicians working in mental health and IAPT settings who will be working with people managing a number of physical health conditions. However, there is the opportunity and some examples of co-working across services (London Strategic Clinical Network, 2014). Joint working can also result in a greater knowledge of referral pathways, improved communication and a shared language. This is particularly appropriate for individuals experiencing the most severe difficulties with their mental health that may or may not be related to diabetes but certainly made more complex by the additional burden of living with diabetes. In contrast, people with less complex issues might best be helped by lower intensity cognitive behavioural therapy (CBT) and would possibly fit the criteria for IAPT. In both instances, there is a need for good communication across the teams involved in their care and for those HCPs providing their mental healthcare to be knowledgeable about diabetes.

There is also a requirement for individual's whose struggles with diabetes are the main contributing factor to their psychological difficulties to have their psychological care provided within the specialist diabetes MDT by a psychological practitioner who is embedded in diabetes. This is usually a clinical psychologist, counselling psychologist or highly trained psychotherapist. This practitioner has a greater depth of knowledge about the interface of diabetes and mental health distress and also supports the diabetes MDT. For people experiencing diagnosable eating disorders, there is a specific requirement for specialist eating disorder services, but with close liaison and joint work with diabetes care.

#### 2. The style and philosophy of care required to support consultations that include emotional well-being

It has been argued that self-management education programmes benefit from an explicit philosophy that underpins the style of relating during their delivery (Skinner et al, 2003). It can also inform the models and theoretical concepts we employ (Entwhistle & Cribb, 2013). This is also the case for individual consultations, particularly where there is a need to explore and acknowledge emotional and psychological issues. Within this context, an internal dialogue may already be in operation for the PLwD that in some way they are not coping as they 'should' and that they may be judged. There is a growing burden of stigma and blame attached to the diagnosis of diabetes called 'the shame and blame disease' by a PLwD taking part in qualitative work in this area (Browne et al, 2013). A bias in media reporting possibly reinforced by experiences in clinical settings has resulted in people believing that they are to blame for their diabetes. Additionally, there is a potential for this stigma to be compounded by the additional burden of considering oneself as also having a psychological problem or mental health condition with its concomitant stigma and public misconceptions (Russler, 2016, Haddad, 2015).

Thus, the attitude and skills of the HCP are crucial to de-stigmatising the clinical encounter facilitating open and honest explorations of the person's experience of living with diabetes (Odiase et al, 2020, Phillips et al, 2020). We have an established lexicon to describe how consultations should ideally be delivered such as person-centred and empowering, but how these are conceptualised and operationalised can vary widely. There are many tools to support clinicians and multiple consultation models (Odiase et al, 2020) including documents such as Language Matters (NHS England, 2018) that specifically highlight the importance of the language that is employed in consultations reinforced by recent evidence of the impact on of HCPs language on diabetes distress (Skinner et al, 2019). Ultimately, the practitioner's style of delivery will be largely influenced by the ethos (spirit or philosophy) of the practitioner and the service in which they work (Odiase et al, 2020, Phillips et al, 2020).

Carl Rogers (1951) was one of the first clinicians who argued that 'core conditions' are required within a consultation to develop a relationship that supports open exploration and discovery. These are well established, and in many fields of research have been found to be linked to outcomes and the therapeutic alliance that is established (Bordin, 1979, Hovarth & Symonds, 1991, Martin et al, 2000). In diabetes, there are specific examples of the power of supporting autonomy (Williams et al 1998), listening and acknowledging (Chew et al, 2018) and empathy (Dambha-Miller et al, 2019). In a two armed intervention listening and acknowledging was found to be just as effective as a specific psychological intervention in tackling diabetes distress (Chew et al, 2018) and in a primary care setting the beneficial impact of practitioner empathy on cardiovascular outcomes has been demonstrated in a large cohort (n=628) with those individuals rating higher clinician empathy in the first 12 months post diagnosis experiencing significantly lower rates of all cause mortality at 10 year follow up.



### 3. Cultural, Organisational and System changes are required

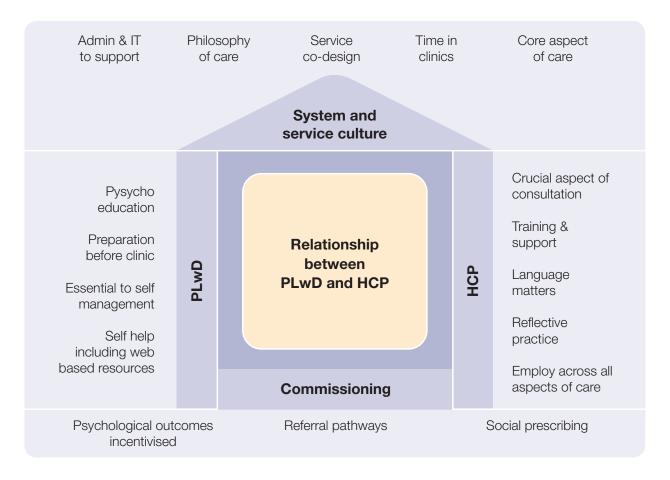
The case is strong for engaging in this way of relating when working with PLwD and other multi-morbidities (The Richmond Report, 2018), specifically when exploring psychological wellbeing and the emotional impact of living with diabetes. There does however seem to be major barriers at an organisational and individual level that have been widely reported (Holt et al, 2013, Johansen et al, 2014, Bryne et al, 2017, Joensen et al, 2018).

A specialist diabetes team set out to integrate a counselling based approach in their consultations (Doherty et al, 2000). The HCPs in this specialist diabetes service reported that it was difficult to engage in this approach due to time constraints in clinic, a focus on biomedical outcomes, anxieties around discussing emotions, ambivalence about whether this was their role and an ethos in the service that did not support this approach. The HCPs lacked confidence in their skills and found themselves reverting back to their old behaviours in consultations. At that time the conclusions were that organisational and system design was required in services to support HCPs to engage more effectively in psychologically informed consultations (Doherty et al, 2000). Almost 20 years later these findings were replicated by a group of HCPs who were asked about the barriers to engagement in consultations with a psychological focus; they include a concern about managing emotions, time constraints, the biomedical focus and again argued that they would require a change in system level change in the clinic culture, guidelines and a move away from a focus purely on biomedical outcomes (Joensen et al, 2018). There have been numerous guidelines and multiple publications of examples of service design. (Diabetes UK, 2019, London Strategic Clinical Network, 2014), but it still proves challenging for conversations about emotional and psychological wellbeing to be fully integrated into routine diabetes care. The barriers are clear including the absence of referral pathways, sufficient training and support and an infrastructure in the clinic that supports HCPs.

Care and support planning is an example of an overall system change that can enhance patient centred conversations and collaborative decisions for people with diabetes and other long term conditions (Roberts et al, 2019, Coulter et al, 2013, Doherty et al, 2012). The success of this endeavour has been based on a focus on ensuring organisational change to transform the consultation alongside ensuring that commissioners support the change and log the changes that are required. The metaphor of a House was employed to emphasise that all aspects of the process need to be addressed collectively; the foundations, walls and roof are required to ensure that the structure is safe, watertight and strong. This has potentially been the challenge to the integration of emotional and psychological well-being into routine consultations. Clinicians trying to engage in these sorts of conversations have said on multiple occasions that they require additional training, ongoing support, time in clinics, referral pathways, recognition of the importance of psychological outcomes alongside biomedical outcomes and ideally for this to be incentivised. This is summarised in Figure 2 with some indicators of the key enablers that need to be in place for change to occur.



#### FIGURE 2: EMOTIONAL AND PSYCHOLOGICAL WELL-BEING HOUSE OF CARE



#### **CONCLUSIONS**

There is much evidence and multiple reviews that demonstrate the importance of supporting the emotional well-being of PLwD. Yet it still remains a neglected aspect of care. The barriers are many including the structure of clinics, biomedical focus, a dearth of support services to refer onto and the HCPs lack of confidence around engaging in conversations that they feel ill equipped to manage.

iDEAL's call to action is for psychological outcomes to be given equal weighting to biomedical indicators. To argue that a whole system approach is required to support the change required to embed this way of working in routine care supported by commissioning, additional training and support for HCPs.



#### **APPENDIX:**

#### **Practitioner and Service Development Resource Guide**

Please find a set of resources to support your journey around supporting clinical consultations that support psychological well-being.

#### Measurement and screening

There is a consensus that the assessment of psychological well-being should be included in diabetes care. The tools recommended by the literature and by the International Consortium of Health Outcomes: https://www.ichom.org/news/ichom-diabetes-standard-set-released-on-world-diabetes-day-2018/are:

- PHQ9 to evaluate depression/low mood
- PAID to evaluate diabetes distress
- WHO5 to evaluate well-being

The type 1 toolkit includes a useful guide to screening measure and pathway to employ: https://healthinnovationnetwork.com/wp-content/uploads/2017/06/TC1-toolkit-final.pdf

The Emotional Health Professionals Guide has recommended measures based on literature review for each area of difficult such as eating issues, anxiety and other psychological responses: https://www.diabetes.org.uk/professionals/resources/shared-practice/psychological-care/emotional-health-professionals-guide

The Behavioural Diabetes Institute provides free copies of diabetes distress tools and a web based tool for electronic assessment: https://behavioraldiabetes.org/scales-and-measures/

### **Practitioner support resources**

Diabetes UK has many support materials in this area one of which is the information prescription 'My emotions and diabetes': https://www.diabetes.org.uk/professionals/resources/resources-to-improve-your-clinical-practice/information-prescriptions-qa. These can be used via primary care IT systems; EMIS Web, Vision and SystmOne.

The Emotional Health Professionals Guide supported by Diabetes UK is an extensive manual that covers many of the common difficulties experienced by PLwD: https://www.diabetes.org.uk/professionals/resources/shared-practice/psychological-care/emotional-health-professionals-guide. Each chapter includes a description of the difficulty, how to raise the issue, assess, support and when to refer on. It also includes patient related information.

Centre for Clinical Interventions develops and provides evidence-based treatments to adults experiencing complex anxiety, mood and eating disorders. It is a useful place to find up to date online resources: https://www.cci.health.wa.gov.au/Resources/Looking-After-Others

Specifically for supporting people with Eating Disorders, there is the Diabetics with Eating Disorders website with resources section: http://dwed.org.uk/ and BEAT Eating Disorders: https://www.beateatingdisorders.org.uk/

#### The person living with diabetes

Many of the resources in the practitioner sections above are relevant for PLwD.

The Emotional Health Professionals Guide has resources in each section for PLwd

https://www.diabetes.org.uk/professionals/resources/shared-practice/psychological-care/emotional-health-professionals-guide

Of course the Diabetes Uk website and their support services including their helpline: https://www.diabetes.org.uk/guide-to-diabetes/emotions

The Centre for Clinical Interventions has useful resources: https://www.cci.health.wa.gov.au/resources

Northumberland, Cumbria, Tyne and Wear have some very helpful self help leaflets: https://web.ntw.nhs.uk/selfhelp/

Diabetics with Eating Disorders http://dwed.org.uk/ and BEAT Eating Disorders https://www.beateatingdisorders.org.uk/
have helpful resources for those struggling with eating issues

#### **Commissioning tools**

http://www.londonscn.nhs.uk/publication/commissioning-recommendations-for-psychological-support/https://www.yearofcare.co.uk/building-your-house



#### The First 5 Steps

iDEAL calls for a whole system approach to support an increased focus on emotional and psychological well-being in routine diabetes care. However, please find below some recommendations for the interested clinician keen to make immediate changes to their practice.

- **1.** Ensure and develop a space in the clinical environment conducive to a holding a private uninterrupted conversation this may require some reorganisation to the clinic process or timing.
- 2. Raise the issue or use preparation tools prior to the consultation such as posters, information leaflets or specific tools like those used in care planning. Many are available via Diabetes UK, and there are examples of care planning tools on https://www.yearofcare.co.uk
- **3.** As confidence grows and develops use information prescriptions or other tools to assist the consultation https://www.diabetes.org.uk/professionals/resources/resources-to-improve-your-clinical-practice/information-prescriptions-ga
- **4.** Further develop your confidence by accessing training in counselling skills. Your Trust may provide training in these skills many organisations have adopted Sage and Thyme training to help their staff who work in areas of high distress http://www.sageandthymetraining.org.uk/ or you could access the via a local University or an course such as Knuston Hall (Kilvert and Fox, 2017) https://www.diabetescounselling.co.uk/
- **5.** Try to develop relationships with mental health colleagues such as psychologists, counsellors or psychotherapists to support you with your consultations.



#### **References:**

- Anderson R, Freedland K, Clouse R, Lustman P (2001) The prevalence of comorbid depression in adults with diabetes: a meta analysis, Diabetes Care, 24, 6, 1069-1078 https:// doi.org/10.2337/diacare.24.6.1069 (accessed 12th March 2020)
- Beckwith A, Phillips A, Halloum H, Doherty Y, Grumitt J, Odiase C, Holmes P (2020) Improving the accessibility and personalisation of nutrition and dietetics in current diabetes care. http://www.idealdiabetes.com (accessed 12th March 2020)
- Bordin E (1979) The generalizability of the psychoanalytic concept of the working alliance, Psychotherapy: Theory, Research & Practice, 16, 3, 252.
- Broadley M, Zaremba N, Andrew B, Ismail K, Treasure J, White M, Stadler M (2019) 25 Years of psychological research investigating disordered eating in people with diabetes: what have we learnt? Diabetic Medicine, 37, 3, 401-408 https://doi.org/10.1111/dme.14197 (accessed 12th March 2020)
- Brown J, Ventura A, Mosely K, Speight J (2013) 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes, BMJ Open, 3:e003384 http://dx.doi.org/10.1136/ bmjopen-2013-003384 (accessed 12th March 2020)
- Byrne J, Davies M, Willaing I, Holt R, Carey ME Daly H, Skovlund S, Peyrot M (2017) Deficiencies in postgraduate training for healthcare professionals who provide diabetes education and support: results from the Diabetes Attitudes, Wishes and Needs (DAWN2) study, Diabetic Medicine, 34, 1074-1083 https://doi.org/10.1111/ dme.13334 (accessed 12th March 2020)
- Chew B, Vos R, Stellato R, Ismail M, Rutten G, (2018)
   The effectiveness of an emotion-focused educational programme in reducing diabetes distress in adults with Type 2 diabetes mellitus (VEMOFIT): a cluster randomized controlled trial, Diabetic Medicine, 35, 6, 750-759.
- Coulter A, Roberts S, Dixon A (2013) Delivering better services for people with long-term conditions: Building the house of Care. The Kings Fund. https://www.kingsfund. org.uk/sites/default/files/field/field\_publication\_file/ delivering-better-services-for-people-with-long-termconditions.pdf (accessed 12th March 2020)
- Dambha-Miller H, Feldman AL, Kinmonth AL, Griffin S (2019) Association Between Primary Care Practitioner Empathy and Risk of Cardiovascular Events and All-Cause Mortality Among Patients With Type 2 Diabetes: A Population-Based Prospective Cohort Study, Annals of Family Medicine, 17, 4, 311-318. https://doi: 10.1370/afm.242 (accessed 12th March 2020)

- deGroot M, Crick KA, Long M, Saha C, Shubrook JH. (2016) Lifetime duration of depressive disorders in patients with type 2 diabetes. Diabetes Care;39(21):2174-2181. https://doi.org/10.2337/dc16-1145 (accessed 12th March 2020)
- Diabetes UK (2019a) Too often missing: Making emotional and psychological support routine in diabetes care. https://www.diabetes.org.uk/resources-s3/2019-05/ Full%20Report\_Too%20Often%20Missing\_Diabetes%20 UK\_May%202019.pdf (accessed 10th December 2019)
- Diabetes UK (2019b) Diabetes and Emotional Health a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes. www.diabetes. org.uk/emotional-health-professionals-guide (accessed 12th March 2020)
- Diabetes UK (2010). Emotional and Psychological Support and Care in Diabetes. www.diabetes.org.uk/ resources-s3/2017-10/Emotional\_and\_Psychological\_ Support \_and\_Care\_in\_Diabetes\_2010%20%28DUK%29. pdf. (accessed 10th December 2019).
- Doherty Y, Hall D, James P, Roberts S, Simpson J (2000) Change counselling in diabetes: the development of a training programme for the diabetes team. Patient Education and Counselling 40, 263-278. https://doi. org/10.1016/S0738-3991(99)00079-8 (accessed 12th March 2020)
- Doherty Y, Eaton S, Turnbull R, Oliver L, Roberts S, Ludbrook S, Lewis-Barned N (2012). Year of care: the key drivers and theoretical basis for a new approach in diabetes care, Practical Diabetes, 29, 5, 183–6. https:// doi.org/10.1002/pdi.1687. (accessed 12th March 2020)
- Entwhistle V, Cribb A (2013) Enabling People to Live Well, The Health Foundation. https://www.health.org.uk/sites/ default/files/EnablingPeopleToLiveWell.pdf (accessed 3rd March 2020)
- Fisher L, Polonsky W, Hessler D (2019) Addressing diabetes distress in clinical care: a practical guide, Diabetic Medicine, 136, 7, 803-812. https://doi.org/10.1111/ dme.13967 (accessed 12th March 2020)
- Funnell M, Anderson R (2004) Empowerment and Self-Management of Diabetes. Clinical Diabetes, 22, 3, 123-127, https://doi: 10.2337/diaclin.22.3.123 (accessed 12th March 2020)
- Haddad P, Haddad I (2015). Mental Health Stigma. British Association for Psychopharmacology (BAP) Articles, https://www.bap.org.uk/articles/mental-health-stigma/ (accessed: 10th February 2020)



- Health Innovation Network & Kings Health Partners (2017) Type 1 Consultation (T1C) Tool: User Guide https://healthinnovationnetwork.com/wp-content/ uploads/2017/01/Type-1-Consultation-Tool-User-Guide. pdf (Accessed 28th February 2020)
- Holt R, Nicolucci A, Kovacs Burns K, Escalante M, Forbes A, Hermanns N, et al. (2013) Diabetes Attitudes, Wishes and Needs second study (DAWN2™): Cross-national comparisons on barriers and resources for optimal carehealthcare professional perspective, Diabetic Medicine, 2013, 30, 789-798.
- Horvath A, & Symonds B (1991). Relation between working alliance and outcome in psychotherapy: A metaanalysis, Journal of Counselling Psychology, 38, 2, 139.
- Joensen L, Fisher L, Skinner T, Doherty Y, Willaing I (2018) Integrating psychosocial support into routine diabetes care: perspectives from participants at the Self-Management Alliance meeting 2016, Diabetic Medicine https://doi. org/10.1111/dme.13836 (accessed 12th March 2020)
- Johansen C, Torenholt R, Homme E, Wittrup M, Cleal B, Willaing I (2014) Barriers to Addressing Psychological Problems in Diabetes: Perspectives of Diabetologists on Routine Diabetes Consultations in Denmark, J.Psychol. Psychother, 4, 141.
- Kilvert, A Fox, C (2017) The diabetes counselling course at Knuston Hall:a 30 year journey. Practical Diabetes, 34, 1, 25-27.
- LLoyd C, Dyer P, Barnett T (2000) Prevalence of symptoms of depression and anxiety in a diabetes clinic population, Diabetic Medicine, 17, 3, https://doi.org/10.1046/j.1464-5491.2000.00260. (accessed 12th March 2020)
- London Strategic Clinical Network (2014) London's Care Pathway for Diabetes. Commissioning Recommendations for Psychological Support, http://www.londonscn.nhs. uk/wp-content/uploads/2015/01/mh-physical-carediabetes-082014.pdf. (accessed 28th February 2020)
- Martin D, Garske J, Davis, M (2000). Relation of the working alliance with outcome and other variables: A meta-analytic review, Journal of Consulting and Clinical Psychology, 68, 3, 438.
- Matta J, Hertwig R (2018) Public beliefs about obesity relative to other major health risks: Representative crosssectional surveys in the USA, the UK and Germany, 52, 4, 273-286. https://doi.org/10.1093/abm/kax003 (accessed 12th March 2020)
- NHS England (2018) Language Matters: Language and Diabetes, Accessed at: www.england.nhs.uk/wp-content/ uploads/2018/06/language-matters.pdf (accessed 10th December 2019)

- Odiase C, Phillips A, Doherty Y, Holmes P, Beckwith A, Halloum H, Grumitt J (2020) How to get the best of your consultations in diabetes care for Health Care Professionals, http://www.idealdiabetes.com (accessed 12th March 2020)
- Peyrot M & Rubin R (1997) Levels and risks of depression and anxiety symptomatology among diabetic adults, Diabetes Care, 20, 4, 585-590. https://doi.org/10.2337/ diacare.20.4.585 (accessed 12th March 2020)
- Phillips A, Halloum H, Grumitt J, Odiase C, Doherty Y, Holmes P, Beckwith A (2020) How to make the most of your consultations in diabetes care with people living with diabetes, http://www.idealdiabetes.com (accessed 12th March 2020)
- Roberts S, Eaton S, Finch T, Lewis-Barned N, Lhussier M, Oliver L, Rapley T, Temple-Scott D (2019) The Year of Care approach: developing a model and delivery programme for care and support planning in long term conditions within general practice, BMC Family Practice, 20, 15, https://doi. org/10.1186/s12875-019-1042-4 (accessed 12th March 2020)
- Rogers C (1951) Client-centered therapy, Boston: Houghton-Mifflin.
- Schabert J, Browne J, Mosely K, Speight J (2013) Social stigma in diabetes: a framework to understand a growing problem for an increasing epidemic, Patient, 6, 1, 1-10. https:// doi: 10.1007/s40271-012-0001-0. (accessed 12th March 2020)
- Skinner T, Cradock S, Arundel F, Graham W (2003) Four Theories and a Philosophy: Self-Management Education for Individuals Newly Diagnosed With Type 2 Diabetes, Diabetes Spectrum, 16, 2, 75-80. https://doi.org/10.2337/ diaspect.16.2.75 (accessed 12th March 2020)
- Skinner T, Joensen L, Parkin T (2019) Twenty-five years of diabetes distress research, Diabetic Medicine, 37, 3, 393-400. https://doi.org/10.1111/dme.14157 (accessed 12th March 2020)
- Entwhistle V, Cribb A (2013) Enabling People to Live Well.
   The Health Foundation. https://www.health.org.uk/sites/default/files/EnablingPeopleToLiveWell.pdf (accessed March 2020)
- The Richmond Group of Charities 2018, Multimorbidity: Understanding the Challenge https:// richmondgroupofcharities.org.uk/sites/default/files/ multimorbidity\_-understanding\_the\_challenge.pdf (accessed 12th March 2020)
- Russler W (2016) The stigma of mental disorders. A millennia-long history of social exclusion and prejudices, EMBO reports, 17, 9, 1250-12153.

**Linked** in iDEAL Diabetes



- Williams, G, Freedman, Z, Deci, E (1998) Supporting autonomy to motivate patients with diabetes for glucose control, Diabetes care, 21, 10, 1644-1651.
- Young-Hyman D, de Groot M, Hill-Briggs F, Gonzalez JS, Hood K, Peyrot M (2016) Psychosocial Care for People With Diabetes: A Position Statement of the American Diabetes Association, Diabetes Care, 39, 2126-2140.