



Foreword

In light of the increasing demand upon NHS diabetes services, achieving good outcomes for people with type 1 diabetes can be a challenge. As the NHS struggles to keep pace with demand and advances in technological solutions for the management of diabetes, the fundamental elements of treatment such as care planning and communication can be lost. This is evidenced in national data sets demonstrating significant variation in the health outcomes of people with diabetes. This consultation tool is specifically designed for the management of type 1 diabetes and provides a holistic approach to care planning, bringing together a measure for psychological wellbeing (diabetes distress) as well as clinical results (HbA1c and Gold Score). Whilst this tool has been developed specifically with type 1 diagetes in mind, with some adaptations this approach could be of value in consultations for people with type 2 diabetes.

The objective underpinning this tool is to reduce the variation in care planning that currently exists across services. It aims to encourage diabetes teams to review how their current provision meets the needs of their local population e.g. in improving access to technology, structured education and access to psychological support. It facilitates the collection of a robust data set which will provide a detailed picture of demand to inform outcomes-based commissioning.

We hope you find the tool and this user guide helpful. We welcome your feedback and suggestions for improvement.

Please contact one of the HIN team or email hin.southlondon@nhs.net

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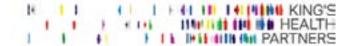














Introduction

This document is a guide for those using the Type 1 consultation tool (T1C) in clinical practice. The tool itself is available in the resources section.

The T1C has been devised by the Health Innovation Network (South London's Academic Health Science Network) diabetes team, with support from King's Health Partners. Its purpose is to give every individual with Type 1 Diabetes access to high quality Type 1 diabetes services, via the introduction of an annual care planning tool.

The T1C is designed to assist you with annual care planning and as such it incorporates auestions on the physical and emotional aspects of living with diabetes, to provide a holistic approach. We recommend that this tool should be completed at least once a year with every person with type 1 diabetes; however you may find aspects of the tool useful to complete at every appointment.

This tool helps you to capture the required key data points for the London type 1 clinical network specification, the National Diabetes Audit and the 2016-17 CCG Improvement and Assessment Framework.

Purpose: The T1C is designed to assist your service in 3 ways



Care Planning Tool: An individual care plan which will consider HbA1c (an individualised target), diabetes distress and hypoglycaemia score. It will enable the clinician and patient to plot results for each of these together onto a circular chart, which will easily demonstrate changes in results and ensures appropriate discussion, care planning and referral if required. The tool also includes questions on structured education, care processes and diabetic complications. It allows the patient to set the agenda and have ownership of the consultation.

- Service Delivery: The overall service results from the tool will help services to highlight the needs of their patients, risk stratify them and plan service provision accordingly. This will enable services to understand demand and share outcomes with commissioners, and ensure that services have the appropriate resources to deliver high auality care.

Type 1 Network: For services in London, anonymous data collected from the use of the tool will be shared at the London Type 1 Network meetings. This data will provide an overall picture of the quality of care for Type 1 patients across London and help to identify opportunities for improvement. By agreeing to use the T1C you are agreeing to share the outcome data measures on page two of the T1C in an anonymous format for the purpose of service benchmarking and to identify opportunities for collaboration.



Download



This user guide is aimed at health care professionals and diabetes multidisciplinary teams. People with diabetes should consult with their healthcare professional as they would normally do, when discussing the management of their diabetes. The Health Innovation Network would like to emphasise that clinical decision making remains the sole responsibility of individual clinicians, and that any information provided is for information and educational purposes only and is not intended to constitute professional advice, diagnosis or treatment, or as a substitute for professional judgement. The Health Innovation Network cannot endorse resources developed by other organisations and therefore individuals and organisations take full responsibility for any use that they undertake of these resources.















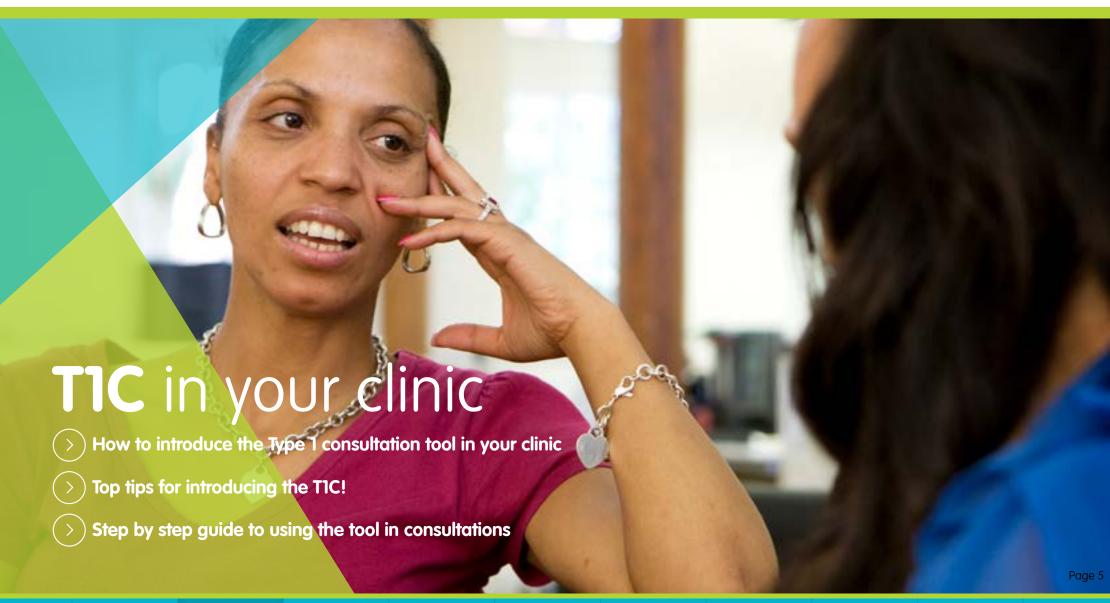


































How to introduce the Type 1 consultation tool in your clinic

Before introducing any change to a clinical setting it is essential to have the involvement of the entire multidisciplinary team, including administration staff and managers. In order to make the change sustainable and part of everyday practice, people whose working practices will be directly affected by the introduction or change need to have their say.

Consider:

- Are staff encouraged to express their ideas and is their input taken on board?
- Are staff able to run small-scale tests (Plan-Do-Study-Act cycles - PDSA) based on their ideas, to see if additional improvements should be recommended?
- What is the mechanism for staff and patients to feed back on their experiences of using the tool?

Find out more about why the HIN developed the T1C

























Top tips for introducing the T1C!

- **Start small** e.g. 1 clinic, 1 day a week and **plan** the organisational processes required to implement for all staff in the clinic including reception staff. Who needs to know about the T1C? How will staff need to change the way they work? What resources will they need? How will you promote it to patients? What are the key messages? e.g. agenda setting.
- Map the process for a patient completing the form, from receiving it in the waiting room (or in advance) to completing it and leaving with a completed care plan. What needs to happen at each stage? How and when will blood tests be completed in advance? Who needs to be informed and how? How will you document and review the care plan next time?
- **Introduce all staff to the changes** and gain support for the team from a senior supporter and create engagement from all staff.
- Agree the process and start & feedback dates
- What else from your consult needs to change? Introducing any new change can initially take longer than existing practice, so consider how you can work as efficiently as possible. Are you already providing psychological screening e.g PAID? If so using DDS2 in the first instance instead could take less time (See **DDS pathway** for more details).

- **Explain the change to patients!** Keeping patients informed of how their consultation may change and how they are expected to prepare for the consultation, (e.g. agenda setting, what they need to bring, what tests should have been completed prior, what to do afterwards) will all help when introducing the T1C in your clinic. In the resources section there is an example of an **explanation sheet**, this can be used to introduce the change to patients.
- **Collecting the data.** What is your process for collecting the data on part 2 of the form? What changes to you need to make to your data collection process? How/who will analyse your data?
- You may not get it right first time! Feedback from our trial sites has told us that it may take a few attempts to discover how to integrate the TIC into a consultation. Don't be discouraged, talk to colleagues, consider the process and keep going!











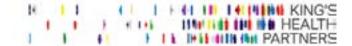




Resources









It is important to ensure that the patient receives the form as early as possible in the process, at check in or if possible sent out with clinic appointments.

Make sure the process is agreed with administration staff and check periodically how this process is working. Ensure you are providing patients with enough time to complete the form – initially you may find that patients are not accustomed to being asked to set an agenda for the visit and they may not know or need help in deciding what to suggest, however on subsequent appointments patients will be more prepared. Care planning enables the individual person with diabetes to identify their own goals, action plans and any support they may need. This becomes a gateway to providing personalised support, which:

- Links traditional clinical care with support for self-management
- Signposts to community resources made available as part of wider local commissioning
- Coordinates health and social care where appropriate
- For you and your patient to get the most out of using the tool it is essential that the most up to date blood results including HbA1c and eGFR are available at the appointment. If point of care testing is not available then this may require the patient to attend for a blood test in advance of their appointment. Patients should also be encouraged to bring along their retinal screening results and this should be clearly requested in the appointment letter.



Dr Pratik Choudhary and Prof Jackie Sturt have made a short film about how to get the most out of the TIC consultations















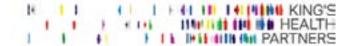














The tool is made up of 3 parts.

Part 1 Preparation for the consultation



Agenda setting

This question should be completed by the patient in advance of seeing the diabetes team, ideally at home or if not then in the waiting room. Initially patients are likely to be unfamiliar with this approach and may not write anything, however experience shows that with repeated use of the tool patients become familiar and comfortable with completing this section. It is good practice to encourage patients to consider completing this before their next appointment.

Agenda setting allows the patient to consider the purpose of the appointment and provides the clinician with an insight into what is most important to the patient. In some cases the most important thing may concern other issues such as finances, relationships and housing. These issues are highly likely to be impacting on the patient's ability to self manage. Whilst the diabetes team may not be able to act to change these issues, simply acknowledging their presence will be useful for planning care with realistic expectations!

This question should also be considered as a recap of the last 12 months. The answers will provide the core information you need which, combined with the context of the patient's agenda, will provide you with key pieces of information to move forward in planning the next 12 months.

P 1 1 1 2 2 10 10 10 10 10 10 10 10 10 10 10 10 10	EALTH	Health Innovation Network South London
Name	NHS Number	Date
Type 1 Diabetes Consultation To This form will help you and your health care Please let us know if you would like any assist Part 1: Please fill this part of Please tell us what would you like to discuss the property of th	professional to plan your diabetes care. stance to complete this form.	ur consultation
O2 Have you had any hospital admissions due to diabetes in the last 12 months? Yes No	O2a If yes how many and when?	
Have you been offered a referral to a structured education course e.g. DAFNE? Yes No	O3a If yes when did you complete the cours	e or complete a refresher?
Q4 Please indicate on the scale how confident NOT CONFIDENT 1 2 3		CONFIDENT













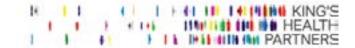


Resources





References





Q2-2a

Hospital admissions

These answers provide an indication of any problems relating to hypo or hyperglycaemia. This information is not always available in clinic and the patient may forget to tell you, especially if this is 'normal' for them.

O2 Have you had any hospital admissions due to diabetes in the last 12 months? Yes No	Q2a If yes how many and when?
O3 Have you been offered a referral to a structured education course e.g. DAFNE? Yes No	Q3a If yes when did you complete the course or complete a refresher?

Structured Education

Structured education is a fundamental part of Type 1 diabetes care. Improvements in patient outcomes as a result of attending are well documented; however we also acknowledge that structured education in its traditional format of 5 days of group education is not suitable for everyone. It is important to include the date a person attended or declined structured education, because they may now be willing to attend.

Q2	Have you had any hospital admissions due to diabetes in the last 12 months?	
	Yes No	
Q3	Have you been offered a referral to a Q3a If yes when did you complete the course or complete a refresher? structured education course e.g. DAFNE?	
	Yes No	
Q4	Please indicate on the scale how confident you are in carbohydrate counting?	
	NOTCONFIDENT 1 2 3 4 5 6 7 VERYCONFIDENT	
Q5	How many hypos have you had in the last year that you were unable to treat by yourself?	









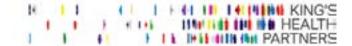












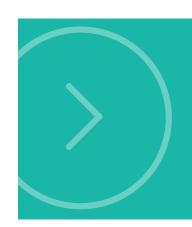




Confidence in carbohydrate counting

Use the answer to this question to explore the reasons behind the score. It may help you to identify patients who already have the skills required for dose adjustment and may need refreshing, or those who have limited or no experience at all. When seeking additional support or training for dose adjustment, consider referral to an appropriately qualified dietitian. Remember that a measure of confidence is not always a measure of competence.

Q3	Have you been offered a referral to a structured education course e.g. DAFNE? Osa If yes when did you complete the course or complete a refresher?	
Q4	Please indicate on the scale how confident you are in carbohydrate counting? NOT CONFIDENT 1 2 3 4 5 6 7 VERY CONFIDENT	
Q.5	How many hypos have you had in the last year that you were unable to treat by yourself?	
Q6	Please indicate on the scale how aware you are of when your hypos are commencing? (Gold Score)	



Online support and additional training can be found at:

Bournemouth Diabetes and Endocrine Centre (BDEC) online www.bertieonline.org.uk

Diabetes UK carb counting E-book www.diabetes.org.uk

Carbohydrate counting APP www.carbsandcals.com

www.inputdiabetes.org.uk

www.tlresources.uk

www.excarbs.com

www.diabetestravel.org

The Health Innovation Network does not endorse resources developed by other organisations, and therefore individuals and organisations take full responsibility for any use that they undertake of these resources.









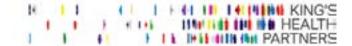














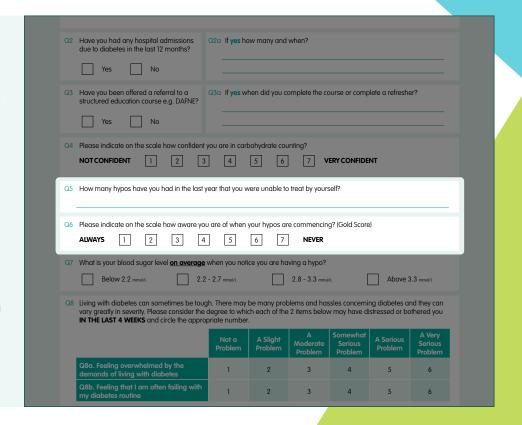


Hypoglycaemia risk

These questions are designed to establish a patient's risk of hypoglycaemia which needs to be determined in order to create a comprehensive care plan. See the **hypoglycaemia section** later in this document for suggestions on how to develop your own local pathway.

The Gold score is a validated tool comprising of a simple 7-point visual analogue scale that can be used by patients to grade their awareness of hypoglycaemia with '1' being always aware and '7' being never aware.

- Scores of 1-2 are normal
- A score of 3 or 4 denotes intermediate awareness.
- Those scoring 4 or above have impaired awareness of hypoglycaemia and in multiple studies have been shown to be at 3-6 fold higher risk for severe hypoglycaemia. Most population surveys show 20-30% of people with type 1 diabetes have impaired awareness, with the risk rising with age and longer duration of diabetes.

















Resources









Hypo awareness

It is important to establish a patient's awareness of hypoglycaemia in order to understand their risk of having a severe hypo. If an individual with Type 1 Diabetes has experienced severe hypoglycaemia in the preceding 12 months, it is important to discuss the treatment options and it is suggested that you consider using the hypoglycaemia pathway – see hypoglycaemia section.

Q6	Please ind	icate on th	ne scale h	now awar			our hypos ar	e commencin	ig? (Gold Score	e)	
Q7	What is yo	ur blood s	ugar leve	on ave	rage when y	ou notice	you are ha	ving a hypo?	_		
	Be	ow 2.2 mm	ol/L		2.2 - 2.7 mm	mol/L		2.8 - 3.3 mmc	I/L	Above	3.3 mmol/L
Q8	vary great	y in severi	ty. Please	e conside		to which			ssles concerni w may have di		





















Acknowledgments









Living with Diabetes (Diabetes Distress Score 2)

These two questions relate specifically to the psychological demands of living with diabetes. We recognised during the work of the Diabetes Improvement Collaborative that across South London that there was a great unmet demand for the acknowledgement, assessment and support for people who are suffering psychologically with the demands or living with diabetes. During the development of the T1C, we worked closely with Professor Jackie Sturt, Professor of Behavioural Medicine in Nursing from King's College London.

The T1C uses the Diabetes Distress Score 2 (DDS2), a screening tool to identify those patients with high diabetes distress. It is a simple 2 question tool that scores with a high degree of sensitivity and specificity people who have diabetes related distress. Due to its concise 2 question score, it was well received in early pilots of the TIC. DDS2 identifies people who may score highly on more detailed psychological screening tools, such as DDS17 or PAID (Problem Areas in Diabetes). Use this opportunity to look into areas of your patients' diabetes which you or your patient may not have had the opportunity to explore before. This can be difficult but it may help to remove barriers that can be hindering your patients from moving forward.

In order to calculate the DDS2 score add the score from question 8a and question 8b together and divide by 2, (to get the average of the two).

More detailed information, including a suggested pathway, can be found in the **Diabetes Distress** section of this guide.

Q2	Have you had any hospital admissions due to diabetes in the last 12 months?	Q2a If yes h	ow many and	when?				
	Yes No							
Q3	Have you been offered a referral to a structured education course e.g. DAFNE?	Q3a If yes w	vhen did you c	omplete the co	ourse or comp	olete a refresh	er?	
	Yes No							
Q4	Please indicate on the scale how confidently NOT CONFIDENT 1 2 3		rbohydrate cou		ERY CONFIDE	NT		
Q.5	How many hypos have you had in the last yo	ear that you	were unable to	treat by yours	self?			
Q6	Please indicate on the scale how aware you ALWAYS 1 2 3 4	. —	your hypos ar	e commencin	g? (Gold Score	el		
Q7	What is your blood sugar level on average with the Below 2.2 mmoth. 2.2	when you no	tice you are ho	iving a hypo?	n [Above :	3.3 mmol/L	
Q8	Living with diabetes can sometimes be toug vary greatly in severity. Please consider the C IN THE LAST 4 WEEKS and circle the approp	degree to wh	ich each of the					
		Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem	
	Q8a. Feeling overwhelmed by the demands of living with diabetes	1	2	3	4	5	6	
	Q8b. Feeling that I am often failing with my diabetes routine	1	2	3	4	5	6	
								Page 1















Resources





References





Part 2 - Data collection

Part 2 of the TIC enables the collection of an agreed set of key metrics that will support you in understanding your local type 1 diabetic community, so that you can develop services appropriately. The majority of information here has already been completed in page 1 of the TIC. Use this section to add to your data and write clinical notes.

The first 4 boxes at the top of the page should be completed using the data from the previous page.

Part 2: You and your healthcare professional will fill this part out together Number of severe hypos in past 12 months (0.5) Gold score (0.6) Todays' HbA1c: (can be from within last 6 weeks! "Living with diabetes" score (DDS) (overage of 0.80 and 0.81) Complications Q9 Please tick existing complications: No complications Stroke/Transient Ishaemic Attack (TIA) Microalbuminuria Ishaemic heart disease Gastroparesis Proteinuria Peripheral vascular disease Peripheral neuropathy	past 12 months (Q.5)" within last 6 weeks			on Tool			
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	Date: Date: Date:			Referred		Declined	
				Date:	D	ate:	
Q11 CSII (Pump) MDI RT-CGM	CSII (Pump) MDI RT-CGM	Q11 C	SII (Pump)	MDI		RT-CGM	
		Q10 Structure	d education status (Q3 an ompleted course or	Referred	D		











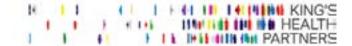














Complications

In order to understand the severity and variation in demand upon a diabetes service it is important to know the amount and complexity of needs of the people using the service. This knowledge will enable a clearer understanding of the demand and what service provision is required to meet it.

You should complete the retinopathy part by grading it into the following categories:

R (Retinopathy): grade 0-3

M (Maculopathy): grade 0-1

P (Photocoagulation): grade 0-1

This information will be provided from the eye screening clinic letter (encourage patients to bring this with them).

More detailed information on the eye screening can be found here:



	TA DESIGNATION PA	RINERS			Sou
Name			NHS Number		Date
Type 1 Diabe	etes Consultation	Tool			
Part 2: You	and your heal	thcare p	rofessional will	fill this _[part out together
Number of severe past 12 months (Q		e (Q6)	Todays' HbA1c: (ca within last 6 weeks)	n be from	"Living with diabetes" score (DDS) (average of Q8a and Q8b)
Complications					
	existing complications: complications		oke/Transient Ishaemic tack (TIA)	R	etinopathy R M P
Mici	roalbuminuria	Ish	naemic heart disease	G	astroparesis
Prot	einuria	Pe	ripheral vascular disease	P	eripheral neuropathy
	tion and therapy:	2.			
Com	education status (Q3 and Q apleted course or esher course		ferred	D	eclined
Date:		Date:		Date:	
Q11 CSII	(Pump)	M	DI	R	T-CGM
Care Processes: (Please add values if kn	iown)			
Q12 Please indic	ate which checks you have	e received in th	ne past 12 months?		
B	slood Pressure		HbA1c		Foot check
	Cholesterol		eGFR/Cr (kidney function)		Smoking cessation
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Introduction









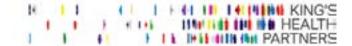




Resources









Therapy

This data should be recorded in order to provide a clear audit of the uptake and outcomes of each therapy.

Q10 Structured education status (Q3 an Completed course or refresher course	Referred	Declined	
Oll CSil (Pump)	Date: MDI	Date:	
Care Processes: (Please add values in	f known) have received in the past 12 months?		

Care processes

Care processes are an integral part of diabetes care. They are a mandatory part of the Quality and Outcomes Framework (QOF) and the National Diabetes Audit (NDA), therefore they are everyone's responsibility. If these checks have not been completed in the last 12 months then you should action this.

Q12 Pleas	e indicate which checks you have	received in	the past 12 months?	
	Blood Pressure		HbAlc	Foot check
	Cholesterol		eGFR/Cr (kidney function)	Smoking cessation
	Urine ACR (Urine protein)		BMI (body mass index)	Retinal screen

Care processes in type 1 diabetes

People with Type 1 diabetes are less likely than people with Type 2 diabetes to receive all of the eight care processes (this excludes eye screening). In 2014-15, 38.7% of people with type 1 diabetes in England and Wales received all the eight care processes compared with 58.7% of people with type 2 diabetes in England and Wales. People aged under 40 are much less likely

to receive their care processes compared with older people for both type 1 and type 2 diabetes. (Source: National Diabetes Audit 2013-2014 and 2014-2015 Report 1: Care Processes and Treatment Targets. Health and Social Care Information Centre, January 2016).























Clinical notes

Use this section to write your clinical notes. In the right hand corner of the box are some prompts which act as a reminder of questions to ask the patients. This ensures that all aspects of the individual's life are covered – these are not mandatory questions but should be considered, more like clothes pegs from which to hang the conversation on!

Exercise – This question will enable you to explore if a person with type 1 diabetes is exercising regularly and if not encourage them to do so. It will also help you consider if they require any support in adjusting their insulin to avoid hypos when they do exercise.

Alcohol – this is about ensuring that individuals are reminded of the effect of drinking alcohol on their glycaemic control and possible subsequent hypoglycaemia the following morning, and that they are aware of measures to prevent hypoglycaemia.

Pre-conception planning - Type 1 diabetes is often diagnosed in childhood or early adulthood. For women of childbearing age* with Type 1 diabetes, pregnancy planning is essential to reduce risks to the mother and baby. Pregnancy planning ensures that issues are identified and minimised to maximise the health of both mother and baby.

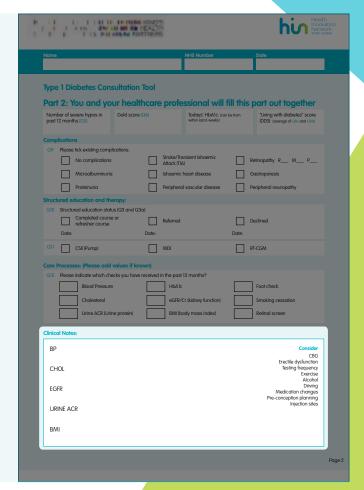
*Childbearing age is defined as the period in a woman's life between puberty and menopause.

Medication changes – any recent changes that could account for changes in glycaemic control – eg steroids

Erectile dysfunction (ED) – prevalence estimates of ED in Type 1 range between 27-75%. Patients often find it difficult to initiate discussion about this and rely on health professionals to initiate the topic.

Driving – See **Resources** section for DVLA regulations.

Smoking cessation – This will enable you to explore if a person with type 1 diabetes is smoking. You should ask open questions to understand how much, and if they are aware of the added risks associated with smoking and type 1 diabetes. Use this opportunity to provide education on risks and options for support with stopping smoking.



















Resources



Acknowledgments



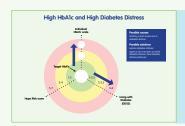




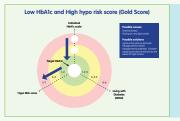
Part 3: Plotting the results

The circular chart in part 3 of the T1C is blank to enable the clinician, in discussion with the patient to plot the HbA1c, DDS2 and Gold Score results from part 1. Together they should agree the desired HbA1c target, which can then be plotted on the graph. This facilitates discussion and individualised goal setting for HbA1c.

We suggest that you plot at least two points for each of the domains (ie at least the last point and today's), so that the trend can be seen. It is challenging to ascertain the story of how well a person is managing their diabetes from one plot of a single moment of time. On the right hand side of the graph there is a recommended HbA1c scale in accordance to NICE guidance, however we acknowledge these targets may not be achievable or desirable for everyone. See **Individualising HbA1c** for more information.



1) High HbA1c, high distress, low hypos consider that the patient may not be taking (enough) insulin and is likely to be missing boluses



3) Low HbA1c, high hypos – this is often seen in overinsulinsed patients who may have perfectionist traits. If distress is high this may be related to fear of HYPERglycaemia, especially if the patient is hypo unaware. This needs to be taken into account when trying to reduce hypos



2) High HbA1c, high hypos (distress may be high or low) – this pattern can indicate chaotic use of insulin and that food and insulin are usually taken at different times

How to plot the scores and what they are telling you

Everyone is different. During early trials three common patterns emerged which we have explained in these charts, but don't forget to work with your patients as individuals.

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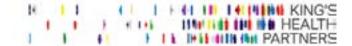




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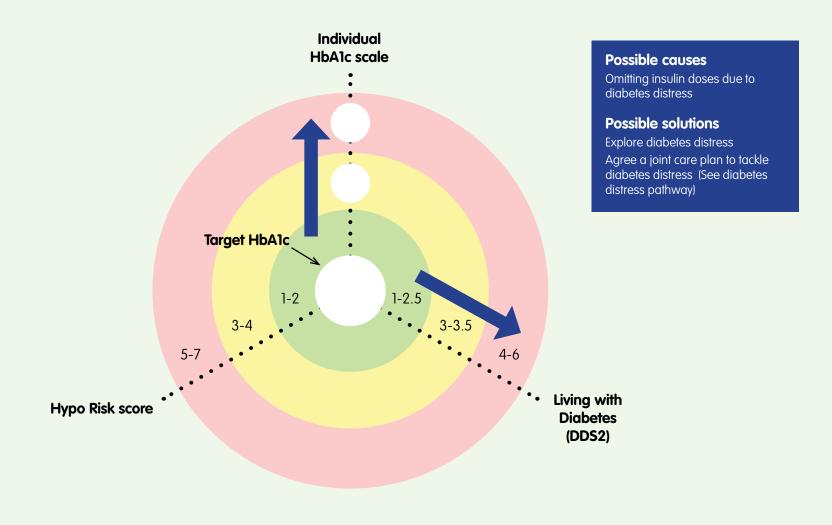


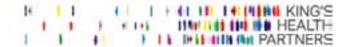






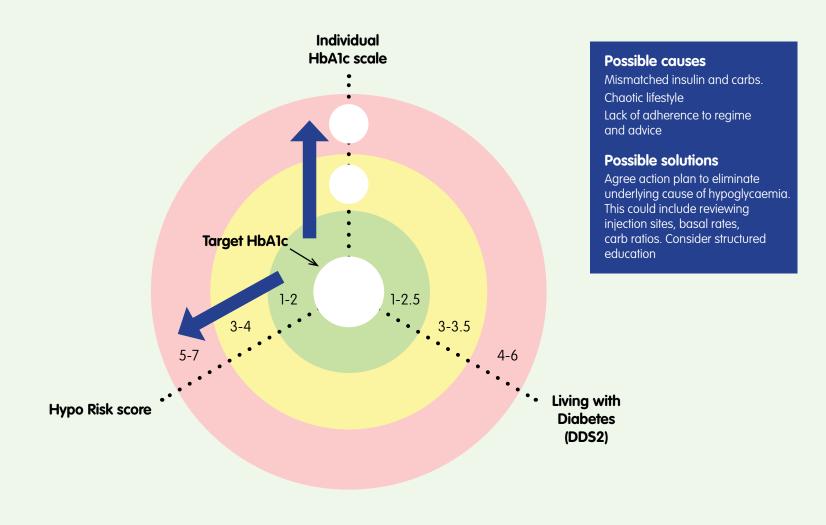
High HbA1c and High Diabetes Distress







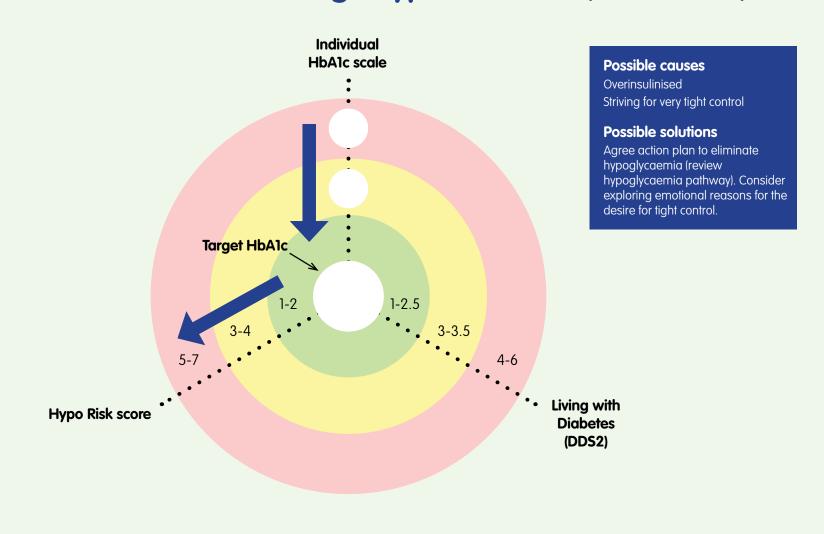
High HbA1c and High hypo risk (Gold Score)

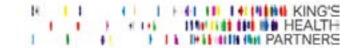






Low HbA1c and High hypo risk score (Gold Score)







Individualising HbA1c

As per NICE guidelines, it is important that a target HbA1c is unique to the individual, and the NICE recommended target of 6.5% may not be appropriate for everyone.

There are a number of factors that should be taken into consideration when individualising the HbA1c.

- 1. Disease duration
- 2. Hypoglycaemia risk
- **3.** Presence or absence of complications
- **4.** Planning pregnancy

It should also be noted that the rate and reliability of insulin absorption also varies on a daily basis, complicating things further. Target HbA1c should be discussed and agreed with the patient.

Are there pitfalls of lowering blood glucose too far?

The 'low as you could go' approach led to several studies to identify whether intensive glucose lowering could reduce macrovascular disease in those at high cardiovascular risk^{1,2,3}. Whilst a reduction in incidence and progression of microvascular disease was demonstrated, the approach had no bearing on macrovascular outcomes. Indeed, one study demonstrated an increased death rate in those treated intensively and an increased incidence of hypoglycaemia².

















Resources



<u>Acknowledgments</u>









Individualising HbA1c

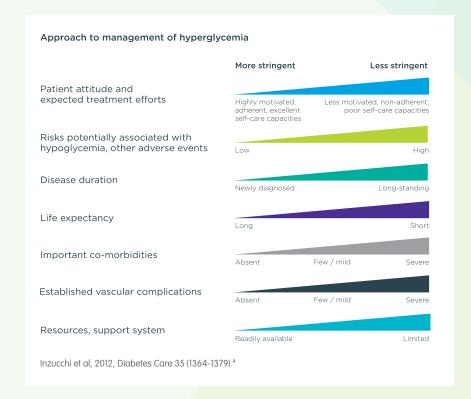
Should we be trying to achieve tight control for all?

There are a number of factors that we need to take into consideration that are largely dependent on individual patient circumstances. Treatment should be individualised to take into account patient preference, length of diabetes and presence or absence of complications. Individual treatment goals should consider the following:

- reducing symptoms caused by high blood glucose such as thirst, polyuria, lethargy and increased number of infections.
- reducing the risk of life-threatening illness through severe hyperglycaemia.
- achieving tight glycaemic control for those with newly diagnosed Type 1 diabetes to reduce the development and progression of both microvascular and macrovascular complications – where it is safe to do so.
- achieving safe, but less tight, blood glucose levels in those with longer duration Type 1 diabetes or those who are at higher cardiovascular risk, frail or elderly.

Ensure that the patient's persistent hyperalycaemia is not caused by high variability due to a lot of hypos, over treating hypos, or deliberately running their HbA1c high to prevent hypos.

This diagram highlights the checks and balances that can be discussed with the individual with Type 1 diabetes when setting a personalised alycaemic target. Although this was originally developed based on research in the Type 2 population, there is no reason why the same points cannot be used as a basis of discussion with an individual with Type 1 diabetes to determine an appropriate individualised HbA1c. However, if appropriate, don't forget to take into account fertility and pre-conception glycaemic targets.





































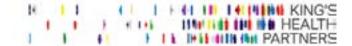














Hypoglycaemia pathway

Severe hypo-glycaemic episodes can have a huge impact on everyday lives of people with Type 1 diabetes, and those around them. Unpleasant symptoms and fear of the consequences of severe "hypos" can reduce independence and spontaneity, significantly impacting on quality of life. Hypos also put pressure on family, colleagues and friends, to be involved in their prevention and management.

A degree of hypoglycaemia (low blood glucose) is inevitable with Type 1 diabetes. On a weekly basis, most adults with well-controlled Type 1 diabetes report that they experience 1-2 episodes of mild-moderate hypoglycaemia that they can self-treat. Symptoms can occur at various glucose levels depending on previous hypoglycaemic experience.

All individuals with Type 1 diabetes should receive education around avoidance of hypoglycaemia, (through structured education) with particular emphasis on:

- Injection sites checking for and avoiding injecting into lipohypertrophy sites
- alcohol
- physical exercise, sport and recreational activities
- travelling, including long distance flights.

All clinical staff working in services for people with Type 1 diabetes should have the expertise to provide appropriate input to those at high risk of problematic hypoglycaemia. It is also suggested that each Type 1 service has a hypoglycaemia pathway – see the hypoglycaemia pathway on the next page as an example that contains the following components

- Structured education such as DAFNE or other local equivalent if not already attended. Such programmes have been shown to reduce hypoglycaemia whilst improving overall glycaemic control. A hypoglycaemia-specific education programme may be considered if available.
- Use of insulin pump therapy. This intervention, implemented by a multidisciplinary team competent in its use, has been shown to reduce frequency of severe hypoglycaemia frequency. Services should follow <u>NICE Technology Appraisal 151</u>.
- Use of blind Continuous Glucose Monitoring (CGM). This can be used with either multi-dose injections (MDI) regime or
 insulin pumps. This is especially useful where insulin pump therapy without CGM has not been successful in reducing
 episodes of severe hypoglycaemia. Recent NICE guidance supports the use of CGM in this context (NG17 1.6.21).

If the skills required for the above measures are not present within the team, or are lost, the team should have a pathway in place to refer these patients to an appropriate service.

• **Islet or Pancreas Transplantation:** For patients where the above interventions are unsuccessful or unsuitable, consideration should be given to refer the person with Type 1 diabetes for assessment of suitability for islet or pancreas transplantation. Islet or Pancreas transplantation is centrally commissioned and provided for those patients who experience frequent severe hypoglycaemia despite best medical treatment. In current circumstances that should include assessment and management at an experienced centre including a trial of insulin pump therapy and continuous glucose monitoring.

There are two Islet/Pancreas transplant services in London, one at the Royal Free London NHS Foundation Trust and the other at King's College Hospital NHS Foundation Trust. We would recommend initial referral for assessment to the Clinical Lead for Islet/Pancreas Transplant services, if patients fit into this category. Data from the King's College Hospital centre suggests that up to two-thirds of patients who meet the criteria for islet transplantation do not require transplantation if provided with access to a specialist hypoglycaemia unit with access to education, psychological support and technology.



















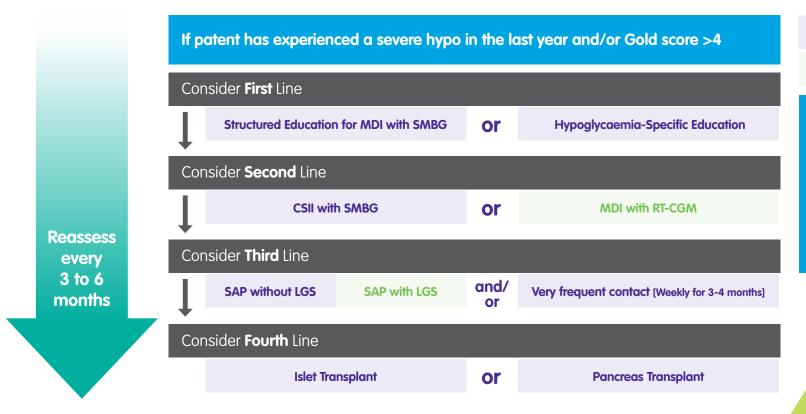




Hypoglycaemia pathway

If an individual with Type 1 diabetes has experienced severe hypoglycaemia in the preceding 12 months, it is important to discuss the treatment options and it is suggested that you consider using the hypoglycaemia pathway.

A suggested Hypoglycaemia pathway



Level I to II Evidence

Level III to IV Evidence

MDI – Multi Dose Injections

SMBG – Self Monitoring Blood Glucose

CSII – Continuous Subcutaneous Insulin Infusion

RT-CGM - Real Time CGM

SAP – Sensor Augmented Pump

LGS – Low Glucose Suspend

Adapted from: Evidence-informed clinical practice recommendations for treatment of type 1 diabetes complicated by problematic hypoglycemia. Choudhary P, et al. Diabetes Care. 2015.5











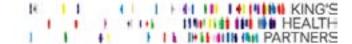














Hypoglycaemia pathway

Driving

Repeated severe hypos can reduce cognitive function, prevent an individual from driving and impact on employment. Certain occupations are barred completely to people on insulin due to the risk of hypoglycaemia.

Recent changes to licensing have been implemented within the European Union which include strict rules around glucose monitoring.

The DVLA provides specific guidance in relation to driving with diabetes, and healthcare professionals should make sure patients with a current driving licence are made aware of the guidelines and that the conversation is documented.



A guide to filling in your DIAB1 medical form

Assessing fitness to drive





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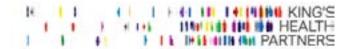






































Hyperglycaemia pathway

Hyperglycaemia - Persistently elevated HbA1c of >69mmol/mol or >8.5%

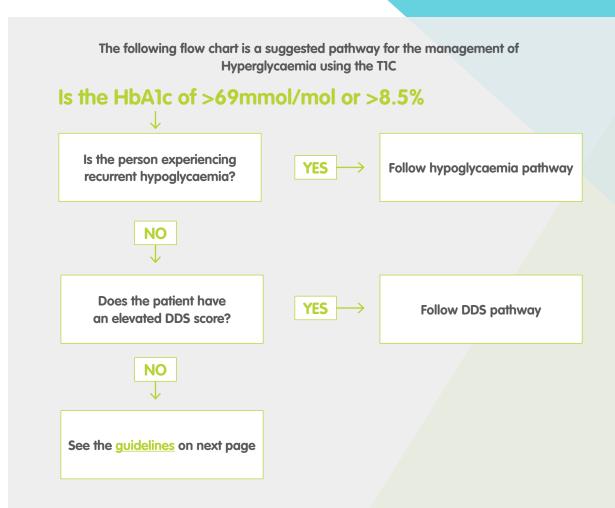
Most adults with well-controlled Type 1 diabetes will experience episodes of **hyperalycaemia** each week. However clinical services should place an emphasis on those who have persistently elevated HbA1c greater than their individualised HbA1c target. NICE guidance for insulin pump therapy (CSII) states that a HbA1c of over 69mmol/mol (>8.5%) and persistent as at least 2 measurements of over 69 mmol/mol (>8.5%) over 6-12 months. can be deemed of concern and support should be in place to enable these individuals to achieve their individualised target HbA1c.

Type 1 diabetes is a complex long term condition, which requires the individual to own the condition for the rest of their life and take responsibility for their health and behaviours. It is a condition which affects the individuals' way of life every hour, every day as glucose profiles and insulin requirements vary on a daily basis depending on multiple factors.

In order to support an improvement in HbA1c it is important to use the T1C tool within an MDT which enables holistic approach. Both hypoglycaemia and Diabetes Distress can impact and result in hyperglycaemia and until both of these areas are managed then it is unlikely that there will be an improvement in the HbA1c.

For example, in an individual with Type 1 persistent hyperglycaemia could be due to high variability due to a lot of hypos, over treating hypos, or deliberately running their HbA1c high to prevent hypos.

Additionally, assessing for disordered eating would be justified in those with very high or persistently raised HbA1c. This is where blinded CGM is useful, as patients may not recognise what is happening themselves.

























Hyperglycaemia pathway

Once Diabetes Distress and hypoglycaemia have been investigated and excluded as a cause of hyperglycaemia then there should be a discussion with the patient to identify and review self-management skills, and any new or on-going educational needs so that the appropriate support to achieve optimal glycaemic control can be offered. *This may include:*

- One-to-one sessions with either dietitian or diabetes nurse or both
- Group educational sessions for example repeat DAFNE course (or equivalent structured education course) or a DAFNE refresher
- Online Support
- Peer Support
- Use of Technology for example Continuous Glucose Monitoring or Bolus Advisors
- Review Injection Sites (does the patient have lipohypertrophy resulting in erratic absorption of insulin?)
- Does the individual require a change in insulin regime?

ACCESS TO TECHNOLOGY

BLINDED CGM REAL TIME CGM INSULIN PUMP APPROPRIATE CAPILLARY BLOOD GLUCOSE TESTING MACHINES

ACCESS TO SERVICES

SPECIALIST CLINICS STRUCTURED EDUCATION GROUP REFRESHER SESSIONS

ACCESS TO PEER SUPPORT

WITHIN ORGANISATION
OUTSIDE OF THE ORGANISATION

ACCESS TO HEALTH PROFESSIONALS

DIETITIAN

DIABETES SPECIALIST NURSE

DIABETOLOGISTS

PSYCHOLOGISTS

SOCIAL CARE SUPPORT

DIABETES EYE / FOOT / KIDNEY TEAM!



















References















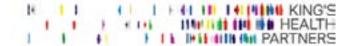














Diabetes Distress

An introduction to Diabetes Distress (DD) and the Diabetes Distress Scale (DDS)

Diabetes Distress (DD) is an emotional response to living with and managing type 1 and type 2 diabetes. It has 4 domains of emotional burden of diabetes: treatment burden, health professional relationship burden and interpersonal burden. Systematic reviews have found Diabetes Distress to be associated with HbA1c⁶ and every 10 point reduction in DD when measured by the PAID scale is associated with a 0.2% reduction in HbA1c7. Elevated DD is also found to be associated with reduced selfcare behaviours relating to physical activity, poorer diet, disordered eating and insulin restriction⁶. The evidence shows a close association between how a person manages their diabetes-related health and their emotional response to diabetes. This makes Diabetes Distress an important clinical area for assessment. 30% of people living with type 1 diabetes will be experiencing elevated DD at this moment and this is affecting their ability to cope with and manage their diabetes.

We are targeting Diabetes Distress, using the DDS Screening Tool, because recent research by Sturt et al.¹²

Diabetes Distress has been assessed for 20 years using the Problem Areas in Diabetes Questionnaire (PAID)⁸ and more recently some of the PAID authors have developed the Diabetes Distress Scale (DDS)9. The DDS9 has been found to provide useful sub scales around the four domains so that the areas in which Diabetes Distress is most elevated can be targeted for additional patient therapeutic support by the diabetes team. These authors have progressed their DDS work to develop a specific type 1 DDS and a DDS 2 screening tool making these scales an ideal suite of diabetes distress assessment scales^{10,11}. We are targeting Diabetes Distress, using the DDS screening tool, because recent research by Sturt et al¹², Diabetes Distress, as opposed to other psychological morbidities such as depression and anxiety, was found to be at the root of most peoples' self-care coping struggles with diabetes and was found to be resolvable within the diabetes clinic setting. For example, structured education such as DAFNE has been shown to be an effective tool to reduce diabetes distress^{6,13,14}. However, Sturt et al¹² found clinical depression was a significant contributor to distress in up to a third of patients with elevated diabetes distress and consequently care pathways beyond the diabetes team are required for these individuals. It is therefore strongly advised that referral pathways to these psychological services such as IAPT are identified before using any tool to assess the psychological demands of diabetes. The flow chart on the next page is an example of a pathway for using DDS2 as a screening tool.

To find out more about the relationship between diabetes and depression, what to look for and how to advise a patient who you suspect may have a major depressive disorder look at the e-learning pages on the King's Health Partners website.



























Diabetes Distress

To calculate DDS2 score Team to pool knowledge and compile and share a booklet/list of resources to support people living with type 1 and long term conditions generally. Add the score of Q8a and Q8b together and divide by 2 = DDS2 score Person with type 1 diabetes completes T1C to record HbA1c, **Ask PHQ2 questions Gold Score and DDS2** NO http://www.cqaimh.org/pdf/tool_ Is DDS score between 2 and 3? phq2.pdf **Calculate DDS2 score** Ask open question like 'Can you $\overline{\mathbf{V}}$ **DDS SCORE OVER 3?** tell me more about the score?' PHQ2 score over 3? $\overline{\bot}$ **YES -** Proceed with consultation **YES -** complete the full PHQ9 NO http://www.psycho-oncology.info/ to explore DDS score. Ask open 1) Proceed with consultation to PHQ9_depression.pdf questions. Complete **DDS17** explore Diabetes Distress Score Is the PHQ9 score 10+ Signpost to support. (complete DDS17 in Resources) (See table on next page) 2) Signpost and refer to support **YES -** refer to Improving Access as per T1C User Guide to Psychological Therapies and GP for diagnosis and treatment for possible major depressive disorder AND proceed with NO - Complete T1C at next consultation to explore routine consultation and monitor DD score (DDS17 in Resources) Go to DDS17























Diabetes Distress

What do I do now that I know the DDS2 score?

DDS score more than or equal to 3

Complete full <u>DDS17</u> and review together

- Identify particular areas of high DDS?
- Ask open questions to explore
- Encourage patient to tell you the detail in 1-2 areas (so they cognitively engage)

Offer additional appointments/contacts

Consider using email/Skype/text consultations to enable more contact

Introduce DAFNE or equivalent as an option and if reluctant discuss timescales and building blocks for future referral

Signpost peer support for those where isolation may be a large factor, ask "Do you know anyone else with type 1 diabetes that you can share experiences with?"

DDS score 2-3

Complete full DDS17 and review together

Identify particular areas of high DDS and problem solve together

Consider using email/Skype/text consultations to add in support (reduce sense of isolation)

Introduce to Diabetes Online Community via Twitter, Facebook, forums

Introduce to local diabetes support groups/expert patient groups

Review structured education needs and perceptions

Complete DDS2 at each consultation and at least 6 monthly

DDS score less than 2

Repeat DDS2 annually and monitor

Consider emotional aspects of diabetes if a rise in HbA1c is observed

Take a preventative approach to Diabetes Distress using the T1C at each appointment

The Health Innovation Network does not endorse opinions and/or views expressed on social media platforms. People with diabetes should consult their healthcare professional as they would normally do, when discussing the management of their diabetes.















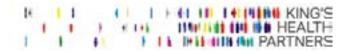
Resources





<u>Acknowledgments</u>

















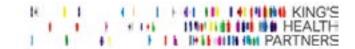














Resources

The Type 1 **Consultation** tool (T1C)











The Large **Text Type 1** Consultation tool (T1C)



You can download the large text T1C



Explanation sheet



You can download an example cover sheet here











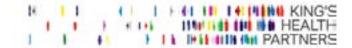














Resources - Psychological assessment tools

Improving Access to Psychological Services (IAPT)

Some patients are likely to benefit from IAPT services (please see suggested flow diagram in Diabetes Distress section). For details on local IAPT services and how to refer (many offer self-referral) please see the directory available here



Diabetes and driving

People with Type 1 Diabetes can be reluctant to share that they've experienced a severe hypoglycaemic episode due to concern over losing their licence – hence it is important to re-iterate that there are things that we can do to support them to prevent hypoglycaemia either via education or the use of technology.

By law a person with any insulin dependent form of diabetes who holds any UK driving licence must inform the DVLA.

Further details of the DVLA regulations and guidance for professionals can be found at the following links:

A guide to filling in your DIAB1 medical form

Assessing fitness to drive





Introduction





















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The members of the London Type 1 Network























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Resources



<u>Acknowledgments</u>

