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MAKING CHOICES: SHOULD I START INSULIN?

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# Healthcare Professionals' Guide to the Patient Decision Aid



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This booklet belongs to:

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# INTRODUCTION

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The purpose of this healthcare professionals' guide is to help you support your patient who is making a decision whether or not to start insulin. The target users for this guide are doctors, diabetes educators and nurses.

## **What is shared decision making?**

In shared decision making, both healthcare professionals and patients are involved in a discussion about the decision during a consultation. Both have the chance to express their views and concerns and come to an agreement eventually on the decision (including not making a change).

## **What are patient decision aids?**

This patient decision aid (PDA) is designed based on the concept of shared decision making. A PDA contains information about the treatment options, their advantages and disadvantages, what is important to the patient and guides them systematically through the decision making process.

In a Cochrane systematic review, PDAs have been found to improve patients' knowledge, help them make decisions according to their priorities and patients become more involved in decision making<sup>1</sup>.

However, a PDA does not replace a clinical consultation. It does not influence patients to choose one treatment option over another but allows them to make an informed decision based on their own priorities and preferences.

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# CONTENTS OF THE PDA

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The PDA contains the following sections:

- **What are your concerns?**

This section highlights common concerns and misconceptions about type 2 diabetes mellitus and insulin.

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- **Information about diabetes and treatment**

This section explains what is insulin and the reasons for starting insulin.

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- **About insulin therapy**

This section explains how one starts insulin and its side effects.

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- **Knowing your blood sugar**

This section explains how blood glucose control can be assessed by using HbA1c, fasting blood glucose and glucometers. The target blood glucose readings are also presented <sup>2</sup>.

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- **What are your choices?**

This section contains the list of treatment options including:

- Do nothing
- Follow stricter diet and exercise programme
- Start insulin injection
- Add another type of diabetes tablet
- Start another type of injection (non-insulin)
- Use alternative treatment

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- **Advantages and disadvantages of the treatment options**

This section provides information about the advantages and disadvantages of the treatment options based on the latest research evidence.

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- **Knowing the facts**

This section contains questions which assess whether the patient has understood the information on the advantages and disadvantages of the treatment options presented in the PDA.

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- **Knowing what is important to you**

This section explores the preferences and concerns of the patient with regards to starting insulin.

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- **Do you need more support?**

This section explores whether the patient needs more information about the treatment options. It also finds out if he has received adequate support from the clinicians and family members.

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- **What is your decision?**

This last section deals with the patient's readiness in making a decision about starting insulin and the option chosen. The patient also has a chance to write down his queries in the space provided.

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# HOW SHOULD I USE THE PDA?

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This PDA can be used at any stage of the decision making process.

## **Before the consultation:**

- The patient can use the PDA while waiting for the consultation or take it back home to read and discuss with the family.

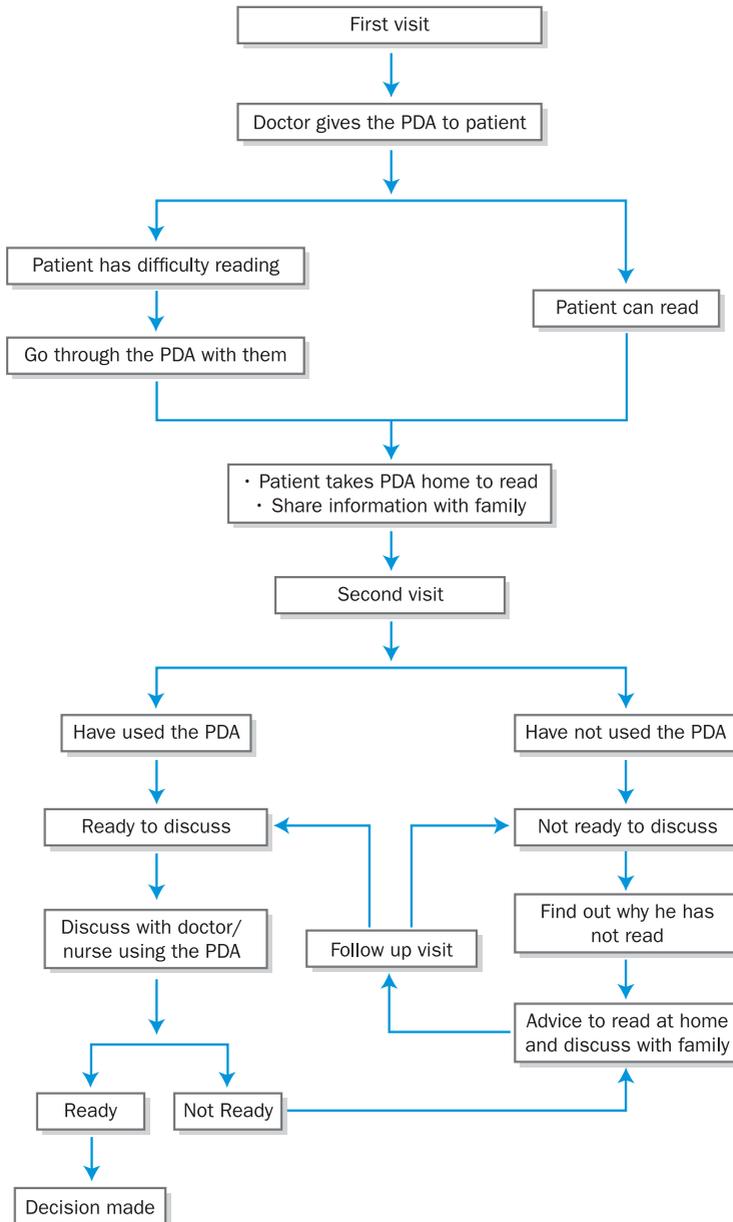
## **During the consultation:**

- The doctor or nurse will ask the patient whether he has read the PDA and is ready to discuss the decision.
- If the patient is ready, the doctor/nurse will go through the PDA with the patient during the consultation.
- If the patient is still not ready to discuss, he can read the PDA at home and discuss with the family.
- If the doctor or nurse does not have time to discuss the insulin initiation with the patient during the visit, the PDA will be discussed with the patient in the next visit.

## **Follow up visit:**

- If the patient is still undecided, the doctor/nurses can discuss further using the PDA to provide further guidance and explanation to the patients to help them to make a decision for insulin initiation.
- If after further discussion the patient is still undecided, he will be encouraged to read the PDA again and write down his concern about starting insulin.
- This PDA can be used over many visits to help patients come to a decision about insulin initiation.

# WHEN TO USE THE PDA?



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# YOUR ROLE AS A HEALTHCARE PROFESSIONAL

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- Assess the literacy of the patient.
- If the patient has difficulty reading, go through the PDA with them in detail.
- If the patient can read, let the patient read the PDA on their own. Do not prompt.
- Explain the content of PDA in more detail if the patient has any queries.
- State the facts but do not influence the patient to start insulin.
- Ensure the patient understand the advantages and disadvantages of each treatment option.
- For patients who are already taking 3 or 4 types (maximum number) of diabetes tablets, 'Adding another type of diabetes tablet' is unlikely to be useful for them. They should consider other choices.
- Discuss the answers with the patient after he has completed the 'Knowing the facts' section (page 12).
  - Answer: Start insulin injection for all questions.
- The patient's needs should be addressed before they make a decision.
- Some patient may take longer to make a decision. Your role is to guide and support them during the process and not to pressure them for a decision.
- Reassure them that they do not need to make a decision now.

# PDA EVIDENCE TABLE

Options	HbA1c	Hypoglycemia
<b>Do nothing</b>	No change or increase	Unkown
<b>Follow stricter diet and exercise programme</b>	No change or decrease	Unkown
<b>Start Insulin injection</b>	Decrease by about 2% <sup>3</sup>	2 to 6 out of 10 people may have hypo <sup>6</sup>
<b>Add another type of diabetes tablet</b>	Depend on the type of tablet – decreases from 0.5 to 1.5% <sup>3,4</sup>	1 to 2 out of 10 people may have hypo <sup>6</sup>
<b>Add another type of injection (non-insulin)</b>	Decreases from 0.5 to 1% <sup>5</sup>	2 to 3 out of 10 people may have hypo <sup>6</sup>
<b>Use alternative treatment</b>	No evidence	Lack of evidence

The research evidence of the PDA is based on a review of the research findings. When discussing the advantages and disadvantages of the treatment options with patients, it is important that you provide accurate and balanced information.

Weight change	Cost per month
Unkown	No added cost
No change or decrease	No added cost
May put on weight by 1 to 2 kg <sup>7</sup>	<ul style="list-style-type: none"> <li>• Insulin: between RM80 – 190 (based on calculation of 10 unit per day)</li> <li>• Strips: RM100 for 50 strips (including meter and pen)</li> <li>• Strips: RM 1 – 2 per strips (25 strips = RM 30 – 50, 50 strips = RM 60 – 100)</li> </ul>
May put on weight from about 0.5 kg to 3 kg <sup>4,7</sup>	Between RM 120 – 240 per month
Weight loss by 1 to 2 kg <sup>5</sup>	Between RM 550 – 600 per pen
Lack of evidence	The cost varies

For example:

- use numbers rather than percentages to explain the risks and benefits. *'2 out of 10 people may get hypos' rather than '20% of patients may get hypos'*
- present the chance of getting as well as not getting complications from their illness. *'2 out of 10 people may get hypos, while 8 out of 10 may not'*

# FREQUENTLY ASKED QUESTIONS

When deciding to start insulin, patients often raise many concerns. The following are scenarios obtained from a study we have conducted with patients and healthcare professionals. Below are suggestions on how you can use the PDA to address the patients' concerns.

Concerns	Patient quotes	Sample response	Page in PDA
<b>INSULIN</b>			
<b>Fear of needles</b>	It will be quite painful. Everyday pain like that I will die!	Insulin pens have fine needles. Most people experience very little pain with the injections.	page 6
	The thing is I don't like poking myself.	You can consider asking family member to do it for you, but most patients have no problem injecting themselves after a while.	
<b>Fear of side effects</b>	A few years ago, I was admitted and they started me on insulin. At that time, every night I sweat and wake up, so I stopped. Now, I know my sugar is not controlled, but I don't want to have that feeling again.	What you are describing is 'hypos'. Insulin may cause 'hypos'. This happens when you skip meals, are not eating enough or exercise too hard. You may feel dizzy, sweaty, cold, confused, shaky and weak.	page 6
		If this happens, you need to take something sweet such as sweets and sugary drinks. You can avoid 'hypos' by eating on time. If it happens too often, inform your doctor and he will adjust the insulin dosage, then you will not have 'hypos'.	
<b>Fear of complication and kidney failure</b>	I thought insulin means very bad already lah.	This is a misconception. High blood sugar level damages the kidneys, not insulin.	page 3-5
	If you don't use your leg for a while, you will have this thing called muscle atrophy. So I was thinking along those lines, the pancreas will go on vacation and become lazy if you use insulin.	Insulin is a hormone produced by the body and it helps to remove sugar from the blood and store it in muscle and fat.	
	Having insulin injection, after a while, the kidney will be damaged.	In diabetes, the blood sugar level is high because the body does not produce enough insulin or it does not respond to insulin properly.	
	Your blood sugar level remains high because your pancreas is not producing enough insulin. In the long term, if the insulin is insufficient, your blood sugar will not be well controlled, and you may get complications such as blindness, heart attack, stroke, kidney failure, nerve damage and losing your toes or legs.		

Concerns	Patient quotes	Sample response	Page in PDA
<b>Scarring from injection</b>	Every day injecting. I am worried it will leave a scar.	Insulin pens have fine needles. Insulin is injected into the skin of your abdomen or the outer part of your thigh. So if you have injected at different sites as your doctor would have advised you, you will not have scars.	page 6
<b>Fear of addiction</b>	I don't want to be a drug addict. Insulin is like a drug addict.	Insulin is not addictive. Unlike recreational drugs, insulin is a hormone and is not addictive.	page 3
<b>Origin of insulin</b>	Is insulin from porcine sources?	All insulin in Malaysia is halal.	page 4
<b>Cost of insulin</b>	Injection is very expensive.	The cost of insulin treatment varies from RM80 – 190. Your doctor will advise you accordingly.	page 4
<b>IMPACT ON LIFESTYLE</b>			
<ul style="list-style-type: none"> <li>• <b>Inconvenience</b></li> <li>• <b>Holiday (storage)</b></li> </ul>	I have to leave for work at 5am. So morning is difficult for me. Night time is ok.	Injecting insulin does not take long when you are familiar with it. Insulin is given by injection using an 'insulin pen'. For most people, one insulin injection at night is all that is needed. You can set the insulin dose you require by turning a dial on the insulin pen.	page 6
	Very inconvenient, when we want to go out everywhere. Like when I go abroad how to bring?	You can travel with the insulin pen without needing special storage.	page 6

# FREQUENTLY ASKED QUESTIONS

Concerns	Patient quotes	Sample response	Page in PDA
<b>DIABETES AND TREATMENT</b>			
<b>Believe that diabetes is not yet serious</b>	I feel that my diabetes is not that serious. I want to observe for a while and see how it goes.	Your blood sugar level remains high despite taking tablets and following healthy diet and exercise. This is because your pancreas is not producing enough insulin.  In the long term, if the blood sugar is not well controlled, you may get complications such as blindness, heart attack, stroke, kidney failure, nerve damage and losing your toes or legs. These complications will affect your quality of life.	page 5
<b>Wants to continue with tablets/ lifestyle</b>	I think I can control my own body. When I cannot control the sugar, it's because I don't do enough exercise. Now I have done enough exercise, I can control my sugar."  Doctor give me tablets is enough already.	Your blood sugar level remains high despite taking tablets and following healthy diet and exercise. This is because your pancreas is not producing enough insulin.  In the long term, if the blood sugar is not well controlled, you may get complications such as blindness, heart attack, stroke, kidney failure, nerve damage and losing your toes or legs. These complications will affect your quality of life.	
<b>STIGMA</b>	Once we have to inject, other people will see it, there is nothing we can do. Everyone will know we have diabetes.	Diabetes is a common chronic disease. So having diabetes is just like have other illnesses such as heart disease that we need to be treated to remain well. So you need not worry about how people look at it.	
<b>COMPLEMENTARY AND ALTERNATIVE MEDICINE</b>	I have come across a traditional medicine in the form of a drink. I want to try that out first.	There is a lack of scientific evidence of the benefits and harms of alternative treatment.	page 11
<b>COMMUNICATION WITH DOCTORS</b>	Whatever the doctor says I can't understand. That's my problem.	This decision aid will help you to understand about insulin. Please discuss any worries with me.	

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