

THE **PAEDIATRIC** AND **ADOLESCENT** INSULIN PUMP DECISION AID



THINKING THROUGH **YOUR DECISION**



The Paediatric and Adolescent Insulin Pump Decision Aid – A Novel Intervention Project (Pandani) Decision Aid
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Authors: Assoc. Prof Christine Stirling, Ms Liz Broad, Dr. Erika Altmann, Ms Karen Demangone.

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How can a decision aid about insulin pump therapy help?

If you are reading this decision aid you must be thinking about changing to insulin pump therapy. This booklet will help you think through whether or not to use an insulin pump.

It will also help you identify other information or resources you may need to help you choose.

Using a decision aid can help you feel more confident about your choice and help you to plan for your change to insulin pump therapy. To use this booklet, read through the steps in order.

There are five steps to making a decision.

Working through the five steps will help you make a decision.

Step 1

Getting clear about your decision



Why are you thinking about moving to insulin pump therapy?

.....

When do you think you should make this decision?

Now?

This week?

This month?

Later?

What is the reason for this time frame?

.....

How close you are to choosing about insulin pump therapy?

I haven't really thought about it yet

I am thinking about the options

I am close to making a choice

I have already made a choice but need reassurance

What are my options?

1. Staying with your existing insulin regime
2. Moving towards insulin pump therapy (IPT).

Are you **leaning** towards any particular option?

Yes No



If Yes, Which one?



Step 2

Identifying what you need to make your decision



Below are some things that we know can help people make decisions. By answering these questions you can find out what support you need to make your decision.

1. Do you have enough support in making your decision?

Yes No

2. Are you choosing without influence from others?

Yes No

3. Do you understand the options that are available to you?

Yes No

4. Are you clear about which potential advantages and disadvantages matter most to you?

Yes No

Now go over your answers to these questions.

People who answer 'No' to one or more of these questions are more likely to delay their decisions, change their minds or feel regret about their decision.

Work through steps three and four.

Focus on meeting your needs.

Feel comfortable and sure about your decision.

Step 3



Exploring your need for decision support

Who else is involved in your decision about using an insulin pump?

(write their names here).

1. Which options do these people prefer?

Person	Preference	Their reason

2. Are any of these people pressuring you?

Yes No

If so, who is pressuring me, and in what way(s)?

Who is pressuring you?	How are they pressuring you?

3. How do their preferences differ from yours?

.....

4. In what ways could these people support you?

.....

5. What role do you prefer when making decisions about your diabetes care?

- I prefer to share the decision making with others
- I prefer to make these decisions myself, after hearing the views of others
- I prefer that someone else decides

6. Who do I want to make the decision (name the person)?

If you would prefer not to make the decision, discuss this with whoever you do want to make the decision.



Step 4



Do you need more information?

Think about the following questions for different options you are considering. You can write down the options you are considering and your answers to the questions or just think about them.

1. What option are you leaning towards considering?

- Current therapy of fixed dose insulin injections or multiple daily insulin injections
- Insulin pump therapy
- Don't know



2. Think about the advantages and disadvantages to you for each option?

Tick the answers in the boxes below if they apply to you. You can add to the list if you think of more. Then go back and put a star next to the most important ones.

Importance	Advantages of current therapy	Advantages of insulin pump therapy (IPT)	Importance
	<ul style="list-style-type: none"> • Lower cost • Less intensive • No new learning required • No change to school/day care support except when starting at a new school. • My BGLs are stable on this treatment 	<ul style="list-style-type: none"> • Greater flexibility in what, when and where you eat. • Greater flexibility in what and when activities are undertaken • Less injections • Easier to administer insulin in a school environment • Lower risk of hypos • Lower risk of hospitalisation for DKA • Greater capacity to correct above target BGL's • Smaller amounts of insulin able to be delivered • Able to connect directly to Continuous Glucose Monitoring (CGM) • Potential for low glucose suspend technology 	

3. Are there any issues you have identified that might influence your decision?

I don't yet have the right skills for managing the pump.

Yes No

I need more help from friends and family with my diabetes management?

Yes No

My school/crèche will need training in pump management.

Yes No

The cost of pump therapy is stopping me.

Yes No

I don't know who to contact when things go wrong.

Yes No

Anything else stopping me?

Yes No

What?

If you answered 'Yes' to any of these questions then you may need additional information or help when changing to insulin pump therapy.

There are a number of scales to help you understand how stress and diabetes related distress may be impacting on the way you experience life. Your diabetes team will be able to recommend a scale appropriate to your circumstances.

In the following section we have listed some areas of life that might influence how well you can manage with insulin pump therapy. This is about how much value you and other people place on these issues. There are some scales to help you decide whether you will need more help with these issues. Place a circle around the number that most reflects how you feel about each question.

Is the timing right?

Timing your transition is crucial for success. Many insulin pump users find a time during school holidays and annual leave is the best time to transition because they are less busy.

Is now a good time for you to transition to insulin pump therapy?

Yes

No





How helpful is your school or crèche environment in managing diabetes therapy?

The level of support you experience at school or crèche will vary. Sometimes a school is very supportive and will have a dedicated person to oversee your treatment. Other schools will not have help available. You may also experience different levels of support from other students in your class, school camp or crèche.

What level of school or crèche support is offered?

Low 1 2 3 4 5 High

Are you at risk of being treated differently or of bullying?

Low 1 2 3 4 5 High

Is changing my school management plan easy?

Yes No

How well do you get along with your diabetes care team?

Especially when you first change to insulin pump therapy, you will need to make extra time to talk, learn and solve issues with your diabetes care team. Some of this may happen by phone or email.

I am able to meet more often

Low 1 2 3 4 5 High



How easily do I solve diabetes issues?

There is a lot of issues solving to do when you move to a new treatment plan. Moving to insulin pump therapy means that you will need to think about how what you do affects your BGLs and what you need to do to get your BGLs under control.

Diabetes treatment issues worry me a lot

Low 1 2 3 4 5 High

Someone is readily available to help when there is an issue

Low 1 2 3 4 5 High



I am prepared to intensify diabetes management

Changing to insulin pump therapy means that your diabetes management will initially increase. It may take up to 6 months for you to get used to it. It will impact on a lot of different areas of your life.

I am ready to intensify diabetes management

Low 1 2 3 4 5 High

I want to learn more about managing diabetes

Low 1 2 3 4 5 High

Managing my diabetes is a high priority

Low 1 2 3 4 5 High



Frequency of self-blood glucose monitoring

Insulin pump therapy is not magic. You will still need to check your blood glucose levels regularly.

I check my BGLs 4 or more times per day

Low 1 2 3 4 5 High

Daily Insulin Diary

Week beginning: 5 July (date) Name: me

Insulin Injections					Monitoring Blood Glucose Levels								Remarks	
	Type	Units given				Breakfast		lunch		dinner		Before bed	Over night	
		B'fast	lunch	Dinner	Before Bed	Before	After	Before	After	Before	After			
Tue	Rapid	6	6	6		4.6		8.5		10.6		9.2	7.6	
	Long				18									
Wed	Rapid	6	6	6		5.2		7.9		8.5		8.7	11.9	
	Long				18									



What is my computer access like?

Your insulin pump will collect a lot of information about when and how often you test your BGLs. It will also show when and how many carbs were eaten and how much insulin was given. Your diabetes team will need access to this information in order to help you solve issues as they arise. The information can be sent to your team via the internet or you can do downloads at their offices.

I have easy access to a computer

Never 1 2 3 4 5 Always

I have easy access to the internet for uploading the pump information

Never 1 2 3 4 5 Always

I am able to upload and send pump information to my diabetes education team easily

Never 1 2 3 4 5 Always

I can visit my diabetes educator to upload pump data easily

Never 1 2 3 4 5 Always



How well do you look after yourself?

High levels of self-care are associated with better outcomes. Self-care includes remembering to check BGL, keeping diabetes appointments, adjusting insulin appropriately for carbs consumed and exercise undertaken.

It may also include getting enough sleep, eating well, personal hygiene, pampering, spending time with family or friends and downtime.

Remember that parents need self-care as well.

I do everything needed to look after myself

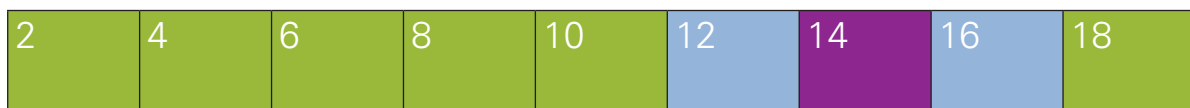
Low 1 2 3 4 5 High



Is this the right age?

Infants, small children and pre teenagers who are regularly monitored by their parents do better on insulin pump therapy provided the child is being cooperative. We've all heard of the 'terrible twos'. That's an uncooperative age, but we might be uncooperative at any age and for a variety of reasons.

I am



How old are you (child or adolescent) and are you in the danger zone?

I am (my child is) co-operative.

Yes No

I think my age / my child's age is a good one for insulin pump therapy.

Yes No

If you are a teenager, you may need to discuss why you want to change to insulin pump therapy and whether this is a good time for you to make the change.

I think my level of maturity is a good one for insulin pump therapy.

Yes No

Would your parents/carers agree with you on this?

Yes No

Change

Moving to insulin pump therapy means change.

Think about what may need to change when using insulin pump therapy.

I will need to change my:

- School or crèche plan:
- Plans for when I stay with friends and relatives
- Information and skills for peers and other people I spend time with
- Sick day management and contacts
- Emergency plans and kits for hypoglycaemia and hyperglycaemia
- Anything else?

Am I ready for change?

Yes

No



Step 5



Planning the next step based on your decision needs

This step is about overcoming things that might be making it hard for you to make a decision about services or resources.

Do you need more information about insulin pump therapy to help you think about what changes are likely to occur?

Yes **No**

If you answered 'Yes', you could try:

Finding information from a diabetes support service – there are some suggestions in the final part of this booklet.

Asking your doctor, endocrinologist, diabetes educator or other health professional for additional information.

Do you feel that you have enough support to make the decision?

Yes **No**

If you answered 'No', you could try:

Discussing your options with a trusted person (eg health professional, councillor, family, friends).

Finding out what help is available to you to carry out your choice (e. g. funding, services in your area).

Do you feel pressure from others to make a particular choice?

Yes No

If you answered 'Yes', you could try:

- Focusing on the opinions of others who matter most.
- Sharing and discussing this guide with other people involved in the care of the person you are caring for.
- Asking these other people to complete their own copy of this guide.
- Looking for areas of agreement. When you disagree on fact, agree to get more information. When you disagree on what matters most, respect the other person's opinion. You need to acknowledge your own values also.
- Finding a neutral person to help you and the other people involved to come to a decision.



Are you unsure about which advantages or disadvantages matter most to you?

Yes No

If you answered 'Yes', you could try:

Going over your responses in step 3 of this guide to remind yourself of what matters most to you.

Finding people who know what it is like to experience the benefits of the options you are considering (e.g. support groups).

Talking to others who have made similar decisions.

Reading stories about what matters most to others.

Support groups often recommend particular books and articles.

Discuss with other what matters most to you.

Are you ready for change?

Yes No



Thank you for using this
decision aid