

# My KETQ & DIAN

Name »

This information is intended for patients referred to a tertiary centre for consideration of Ketogenic Dietary Therapy.

Nutricia's range of ketogenic products are Foods for Special Medical Purposes for the dietary management of drug resistant epilepsy and must be used under medical supervision.







#### STARTING KETOGENIC DIETARY THERAPY!

Your neurologist has recommended that your child starts ketogenic dietary therapy. An exciting new phase is about to start in which you will learn and experience change. You will learn about **nutrition**, **calculating meals** for your child and how you **can prepare tasty dishes**.

Every new beginning can bring challenges and starting the ketogenic diet is no different. The initial phase will likely involve some trial and error as you and your child adjust to the diet. **But you are not facing this challenge alone!** You have an experienced epilepsy team consisting of the neurologist, dietitian and sometimes a nurse who will help you. There are also useful resources such as **ketogenic calculation programmes, booklets and websites full of tips and recipes**.

My Keto Diary will help you during the first 3 months of ketogenic dietary therapy. You will keep track of what you and your child will experience whilst trialling ketogenic dietary therapy. This is important because it it will enable you and your child's epilepsy team to fully evaluate you and the team managing your child's epilepsy to fully evaluate and appreciate the effect of your 3 month trial of ketogenic dietary therapy. My Keto Diary also gives you handy tips and ideas!

#### **NUTRICIA KETOGENICS**

Nutricia Ketogenics is a **pioneer in ketogenic dietary therapy**. Our mission is to ensure diet therapy is accessible to all patients who may benefit from it whilst providing products and services to help make the ketogenic diet easier and more convenient.

We know that the daily implementation of ketogenic diet therapy can be challenging for you. We have developed My Keto Diary **together with neurologists and dietitians to support you on your ketogenic journey**.

# HOW TO USE MY KETO DIARY



My Keto Diary will help you during the **first 3 months** of ketogenic dietary therapy. We recommend you spend just a few minutes filling it in each day. Do not worry if you skip a day or you don't fill something in. However, the more information you are able to write down, the more valuable it will be when you look back at your experience with your child's epilepsy team. This will enable you to make better decisions together about the future in relation to your child's epilepsy.

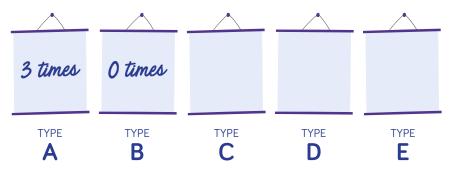
You will **keep track of 4 things** in My Keto Diary: ketone and glucose levels, epileptic seizures, how you and your child are doing and your thoughts about the past week.

#### 1. Epileptic seizures

On the next page of My Keto Diary, you and your neurologist or epilepsy nurse will assign a different letter to the different types of epileptic seizures that your child can experience. Each type of seizure gets its own letter: A, B, C, D or E. In My Keto Diary you can indicate every day what type of seizure(s) your child has experienced and how many.



Underneath the table, you can add up the total number of seizures per week, per type of seizure. For example:



#### 2. Ketone and glucose levels

You can fill in up to **2 ketone and 2 glucose levels per day** as requested by your epilepsy team for eg. in the morning and the afternoon/early evening.



#### 3. This is how my child and I are doing...

Wherever possible try and answer the question of the day. The subjects are varied and can be interesting to think about. You can write down anything that is important to you in relation to your ketogenic diet journey.

#### 4. We thought that this week...

This is where you can indicate **your thoughts and feelings about the week**. Draw a smiley or upside-down smiley face. It may be fun to do this together with your child!



Various pages in My Keto Diary also contain spaces where you can write something down. For example, something that you are proud of, what you have learnt or your favourite recipes. It's **your Keto Diary** so you can write down anything you want so you can so you can refer back to it in time.



## MY CHILD AND OUR KETOGENIC **MANAGEMENT TEAM**





#### Our ketogenic team

NAME	TELEPHONE NUMBER	E-MAIL ADDRESS

#### Types of epileptic seizures

(fill this in together with your neurologist!)

The time in together with good neorotogist.)
Type A:
Type B:
Type C:
Type D:
Type E:

### **GETTING STARTED WITH** KETOGENIC DIETARY THERAPY



My thoughts and foolings about the ketagonic distr

ny thoughts and reetings about the ketogenic diet:
What I hope to achieve with ketogenic dietary therapy:
The total number of seizures per typical week that my child has had approximately:
Type A: Type B: Type C: Type D: Type E:
The following is important for my child's quality of life:

#### In the past month, my child's average quality of life score is:

(1 = very poor, 5 = very good)

✓ Epileptic seizures	1 2 3 4 5
✓ Physical (for instance pain, bowel movement, nausea)	1) (2) (3) (4) (5)
✓ Social & emotional (for instance contact with others, mood)	1 2 3 4 5
✓ Behaviour (eg. passionate, cooperative)	1 2 3 4 5
✓ Cognitive (eg. alertness, speech/language, memory)	1 2 3 4 5





#### **TIPS & PERSONAL NOTES**

Everything is new in the first week and you may feel uncertain. Your dietitian has explained a lot to you and given you all the information you need. Now you get to put it into practice yourself, which is quite exciting.

You will almost certainly have questions and you may want to consult parents in the same situation as you. Do get in touch with Matthew's Friends and The Daisy Garland Charity for extra support.

#### www.matthewsfriends.org www.thedaisygarland.org.uk

There are also closed Facebook groups of parents who have experience with ketogenic diet therapy for refractory epilepsy.

I'm so proud of myself! For the first time I have:



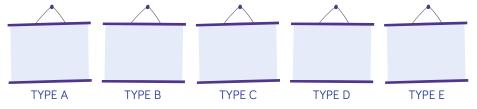
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KETO DIARY | 7 |

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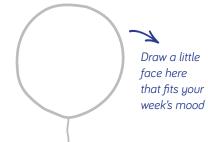
SEIZURE TYPES AND HOW MANY KETONES						SEIZURE TYPES AND HOW MANY KETONES GLUCO			
A	В	С	D	Е	АМ	РМ	АМ	РМ	

# The total number of seizures this week:



We found that this week...





HOW ARE MY CHILD AND I DOING THIS WEEK

DAY OF WEEK:	QUESTION OF THE DAY (provide a detailed explanation for each answer)
	Today, my <b>score</b> for my child's <b>quality of life</b> is:  (circle a number between 1-10, where 1 is very bad and 10 is very good).
	When I was making a <b>ketogenic meal</b> today I thought:
	When I discuss <b>ketogenic diet therapy</b> with others, for example with family or
	friends, I notice:
	I did this today for the <b>first time</b> :
	When I see how my child and other family members interact, I see:
	The influence of ketogenic diet therapy on my own quality of life is:
	Today my <b>child's reaction</b> to their ketogenic meal was:





### TIPS & PERSONAL NOTES

Have you received a copy of the 'What is Ketogenic Diet Therapy' pocket book from your dietitian? This handy booklet contains an overview of ketogenic diet therapy that might be helpful to explain to others.

**Tip:** ask for an a few extra booklets, as required so that you can share them with family members and your child minder or school etc. This way they will also understand why your child has started ketogenic diet therapy and and will be better able to support you both.

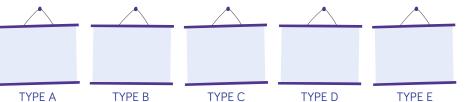
I find this tricky:



as a dire	<b>experien</b> ct or indirect	relation to y	our ketoger	nic journey	

	SE	EIZURE TY	IZURE TYPES AND HOW MANY KETONES			DNES	GLU	COSE	
DAY OF WEEK:	Α	В	С	D	Е	AM	РМ	AM	PM

# The total number of seizures this week:



We found that this week...





# HOW ARE MY CHILD AND I DOING THIS WEEK

DAY OF WEEK:	QUESTION OF THE DAY (provide a detailed explanation for each answer)
	Does my child feel different from other children? If so how?
	Do I see my child's concentration or attention changing? If so how?
	Do I see that <b>my child's emotions</b> and <b>mood</b> are changing? If so how?
	Do I see that my child is <b>changing socially</b> when interacting with others?
	Does my child have <b>physical discomfort</b> (such as abdominal pain, constipation or nausea)?
	Do I see changes in my child's behaviour? If so what changes?
	Do I see my child's sleep patterns change? If so what changes?





### TIPS & PERSONAL NOTES

Other parents and carers often cook large quantities of keto dishes and freeze them in batches. This way you don't have to cook every day. It is useful to always have something on hand, for unexpected circumstances.

Please note: ketogenic food can be oily so it should be frozen soon after preparation. That way it will store well.

I am proud of my child this week because:

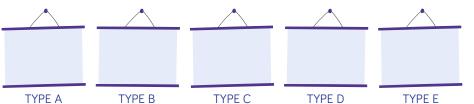




as a dir	ect or indire	ect relation	to your ke	etogenic jo	urney	

SEIZURE TYPES AND HOW MANY KETONES						SEIZURE TYPES AND HOW MANY KETONES GLUCO			
A	В	С	D	Е	АМ	РМ	АМ	РМ	

# The total number of seizures this week:



We found that this week...





# HOW ARE MY CHILD AND I DOING THIS WEEK

Do I see that my child's alertness is changing? If so how?  When I see how my child and other family members interact, I s  The influence of ketogenic diet therapy on my own quality of I  When I discuss ketogenic diet therapy with others, for example friends, I notice:  How does ketogenic diet therapy change your child's life:	
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When I discuss <b>ketogenic diet therapy</b> with others, for example friends, I notice:  How does ketogenic diet therapy <b>change</b> your child's life:	ee:
friends, I notice:  How does ketogenic diet therapy change your child's life:	ife is:
	e family or
I did this today for the <b>first time</b> :	
Today my child's reaction to their ketogenic meal was:	





### TIPS & PERSONAL NOTES

It will be helpful to always keep a stock of ketogenic food products at home to support your ketogenic cooking. This will give you the flexibility to add them as required at the last minute to make meals and snacks more ketogenic.

**In the kitchen cupboard:** tins of asparagus or mushrooms and oils.

**In the fridge:** butter, cream and mascarpone.

**In the freezer:** raspberries, strawberries, blackberries, or gooseberries.

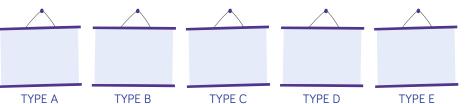
My child's favourite recipe is:



as a dire	<b>experienc</b> ct or indirect re	lation to your	ketogenic joui	ney	

	SE	EIZURE TY	PES AND	HOW MAI	KETO	DNES	GLUCOSE		
DAY OF WEEK:	Α	В	С	D	Е	AM	РМ	AM	РМ

# The total number of seizures this week:



We found that this week...





# HOW ARE MY CHILD AND I DOING THIS WEEK

DAY OF WEEK:	QUESTION OF THE DAY (provide a detailed explanation for each answer)
	Does my child feel different from other children? If so how?
	Do I see my child's concentration or attention changing? If so how?
	Do I see that <b>my child's emotions</b> and <b>mood</b> are changing? If so how?
	Do I see that my child is <b>changing socially</b> when interacting with others?
	Does my child have <b>physical discomfort</b> (such as abdominal pain, constipation or nausea)?
	Do I see changes in my child's behaviour? If so what changes?
	Do I see my child's sleep patterns change? If so what changes?



# Week 5



### TIPS & PERSONAL NOTES

You can easily vary your dishes by adding carbohydrate free flavourings. A basic product such as cottage cheese or creme fraiche is easy to flavour in this way.

**Note:** read the nutrition table on the flavouring and consult your dietitian because liquid flavors can still contain carbohydrates.

This is what I discovered this week:

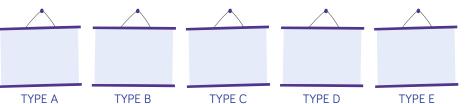




as a d	<i>EXPERI</i> rect or indir	ect relation	i to your i	ketogenic	Journey	

	SI	EIZURE TY	PES AND	HOW MAI	NY	KETO	ONES	GLUCOSE	
DAY OF WEEK:	Α	В	С	D	E	АМ	РМ	АМ	РМ

# The total number of seizures this week:



We found that this week...





Draw a little face here that fits your week's mood

# HOW ARE MY CHILD AND I DOING THIS WEEK

DAY OF WEEK:	QUESTION OF THE DAY (provide a detailed explanation for each answer)
	Do I see that <b>my child's alertness</b> is changing? If so how?
	When I see how my child and other <b>family members interact</b> , I see:
	The influence of <b>ketogenic diet therapy</b> on my own <b>quality of life</b> is:
	When I discuss <b>ketogenic diet therapy</b> with others, for example family or friends, I notice:
	How does ketogenic diet therapy <b>change</b> your child's life:
	I did this today for the <b>first time</b> :
	Today my child's reaction to their ketogenic meal was:





### TIPS & PERSONAL NOTES

You can use silicone moulds to make small portions that you can freeze. Aluminum foil or silicone sheets also work well with oily dishes; unlike baking paper which just absorbs the fat.

**Tip:** Use a spatula to scrape out pots and containers. After all, you don't want to lose any valuable morsels when transferring food to your child's plate.

My child played

and Tadded:

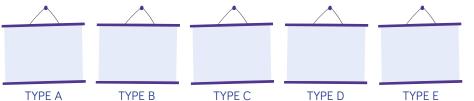
as a snack



6	<b>Gur ex</b> is a direct	or indired	t relatio	n to you	r ketoge	nic journ	ey	

	SE	EIZURE TY	PES AND	HOW MAI	KETO	DNES	GLUCOSE		
DAY OF WEEK:	Α	В	С	D	Е	AM	PM	АМ	РМ

# The total number of seizures this week:



We found that this week...









# HOW ARE MY CHILD AND I DOING THIS WEEK

DAY OF WEEK:	QUESTION OF THE DAY (provide a detailed explanation for each answer)
	Does my child feel different from other children? If so how?
	Do I see my child's concentration or attention changing? If so how?
	Do I see that <b>my child's emotions</b> and <b>mood</b> are changing? If so how?
	Do I see that my child is <b>changing socially</b> when interacting with others?
	Does my child have <b>physical discomfort</b> (such as abdominal pain, constipation or nausea)?
	Do I see changes in my child's behaviour? If so what changes?
	Do I see my child's sleep patterns change? If so what changes?







### TIPS & PERSONAL NOTES

It is really important to ensure the staff at your child's school have a good understanding of ketogenic dietary therapy. This will ensure your child does not miss out and and enjoy school trips, for example.

#### Tips:

- Give you child ketogenic snacks to enjoy so that they don't miss out at snack time with their school friends.
- Make sure that your child's teacher has a tin of ketogenic snacks: when a classmate has a treat, there is always a treat for your child. Perhaps in the morning you can put a ketogenic muffin in his / her school bag!

My top tip to a parent who is just starting ketogenic diet therapy is:

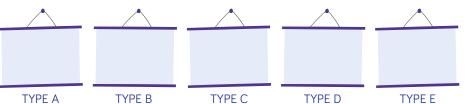




as a dire	ect or indired	ct relation to	your ketog	<b>k:</b> enic journey	

	SI	EIZURE TY	PES AND	HOW MAI	NY	KETO	ONES	GLU	COSE
DAY OF WEEK:	Α	В	С	D	E	АМ	РМ	АМ	РМ

# The total number of seizures this week:



We found that this week...





Draw a little face here that fits your week's mood HOW ARE MY CHILD AND I DOING THIS WEEK

DAY OF WEEK:	QUESTION OF THE DAY (provide a detailed explanation for each answer)
	Do I see that <b>my child's alertness</b> is changing? If so how?
	When I see how my child and other <b>family members interact</b> , I see:
	The influence of <b>ketogenic diet therapy</b> on my own <b>quality of life</b> is:
	When I discuss <b>ketogenic diet therapy</b> with others, for example family or friends, I notice:
	How does ketogenic diet therapy <b>change</b> your child's life:
	I did this today for the <b>first time</b> :
	Today <b>my child's reaction</b> to their <b>ketogenic meal</b> was:





### TIPS & PERSONAL NOTES

Do you know about MyKetoPlanner? It is a free online tool to support the ketogenic community with recipe development and sharing. It has many delicious ketogenic recipes to give you inspiration for your child's daily menu. Every month there are new recipes added. With the search function and filters you will quickly find an appropriate recipe. ask your Dietitian to register you today.

Tip: make a weekly meal planner to help you organise your shopping and cooking to make life a little easier. Make a note of what you have in the freezer and which MyKetoPlanner recipes you are going to make.

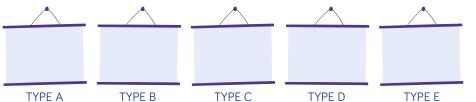
What recipe have you made yourself? Share it on MyKetoPlanner for other parents to try:



as a d	<i>P <b>EXPER</b></i> irect or indi	rect relatio	n to your	ketogeni	journey	h	

	SEIZURE TY		PES AND	HOW MAI	NY	KETO	ONES	GLU	COSE
DAY OF WEEK:	A	В	С	D	E	АМ	РМ	АМ	PM

# The total number of seizures this week:



We found that this week...





# HOW ARE MY CHILD AND I DOING THIS WEEK

DAY OF WEEK:	QUESTION OF THE DAY (provide a detailed explanation for each answer)
	Does my child feel different from other children? If so how?
	Do I see my child's concentration or attention changing? If so how?
	Do I see that <b>my child's emotions</b> and <b>mood</b> are changing? If so how?
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	Do I see changes in my child's behaviour? If so what changes?
	Do I see my child's sleep patterns change? If so what changes?









### TIPS & PERSONAL NOTES

every week you will be improving your skills as a ketogenic cook! Now you can tweak recipes (for example from MyKetoPlanner) so they are suitable for your child. Enter the ingredients and choose the right quantities.

**Tip:** you can make a regular recipe ketogenic by replacing certain ingredients:

- For cakes with apples, replace them with a few raspberries.
- Replace chocolate with cocoa powder without sugar.
- Replace flour with KetoCal powder, almond powder, soy flour or coconut flour.
- Replace potatoes with celeriac, pumpkin, carrot, cauliflower, celeriac or turnip.



This week I'm going to experiment with making a ketogenic version of this dish:

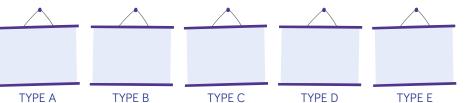




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	SEIZURE T		PES AND	HOW MAI	٧Y	KETO	ONES	GLU	COSE
DAY OF WEEK:	Α	В	С	D	E	АМ	РМ	AM	РМ

# The total number of seizures this week:



We found that this week...





# HOW ARE MY CHILD AND I DOING THIS WEEK

DAY OF WEEK:	QUESTION OF THE DAY (provide a detailed explanation for each answer)
	Do I see that <b>my child's alertness</b> is changing? If so how?
	When I see how my child and other <b>family members interact</b> , I see:
	The influence of <b>ketogenic diet therapy</b> on my own <b>quality of life</b> is:
	When I discuss <b>ketogenic diet therapy</b> with others, for example family or friends, I notice:
	How does ketogenic diet therapy <b>change</b> your child's life:
	I did this today for the <b>first time</b> :
	Today my child's reaction to their ketogenic meal was:





### TIPS & PERSONAL NOTES

You can use silicone moulds to make small portions that you can freeze. Aluminum foil or silicone sheets also work well with oily dishes. Unlike baking paper, which absorbs it.

**Tip:** Use a spatula to scrape out pots and containers to ensure you transfer all the food to your child's plate.

My child played

and I added:

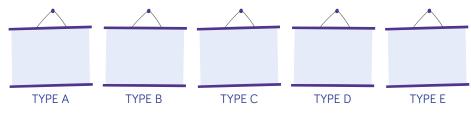
as a snack



as a direc	<b>Xperienc</b> t or indirect re	elation to you	ur ketogenio	journey	

	SE	IZURE TY	PES AND	HOW MAN	NY	KETO	GLUC	COSE	
DAY OF WEEK:	A	В	С	D	E	AM	PM	AM	PM

# The total number of seizures this week:



We found that this week...





# HOW ARE MY CHILD AND I DOING THIS WEEK

DAY OF WEEK:	QUESTION OF THE DAY (provide a detailed explanation for each answer)	•
	Does my child feel different from other children? If so how?	
	Do I see my child's concentration or attention changing? If so how?	
	Do I see that <b>my child's emotions</b> and <b>mood</b> are changing? If so how?	
	Do I see that my child is <b>changing socially</b> when interacting with others?	?
	Does my child have <b>physical discomfort</b> (such as abdominal pain, constipation or nausea)?	
	Do I see changes in my child's behaviour? If so what changes?	
	Do I see my child's sleep patterns change? If so what changes?	





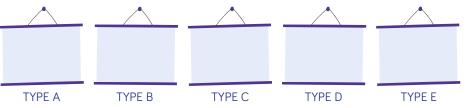
### TIPS & PERSONAL NOTES



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	SI	EIZURE TY	PES AND	HOW MAI	NY	KETO	ONES	GLU	COSE
DAY OF WEEK:	Α	В	С	D	E	АМ	РМ	АМ	РМ

# The total number of seizures this week:



We found that this week...





# HOW ARE MY CHILD AND I DOING THIS WEEK

DAY OF WEEK:	QUESTION OF THE DAY (provide a detailed explanation for each answer)
	Do I see that <b>my child's alertness</b> is changing? If so how?
	When I see how my child and other <b>family members interact</b> , I see:
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	When I discuss <b>ketogenic diet therapy</b> with others, for example family or friends, I notice:
	How does ketogenic diet therapy <b>change</b> your child's life:
	I did this today for the <b>first time</b> :
	Today <b>my child's reaction</b> to their <b>ketogenic meal</b> was:
	Today my child's reaction to their ketogenic meal was:







# **TIPS & PERSONAL NOTES**

Nowadays there are many wannabe masterchefs
who like to cook delicious food. Maybe you have
family or friends who would take up the challenge
of making ketogenic meals or snacks with you?
This could be a nice opportunity to get together
on a Sunday afternoon for example and try
cooking recipes together.

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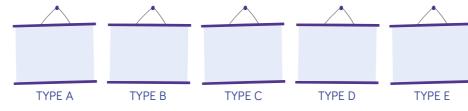
to cook with me



<i>periences the</i> rindirect relation to		

	SEIZURE TYPES AND HOW MANY			KETO	ONES	GLUC	COSE		
DAY OF WEEK:	Α	В	С	D	E	AM	РМ	AM	PM

# The total number of seizures this week:



# We found that this week...





# HOW ARE MY CHILD AND I DOING THIS WEEK

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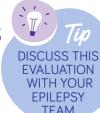
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DAY OF WEEK:	QUESTION OF THE DAY (provide a detailed explanation for each answer)	
	I have learned a lot in recent weeks. For example:	
	It was difficult to:	
	It was <b>not as bad as I thought</b> to:	
	An important result of the ketogenic diet therapy for my child is:	
	An important result of the ketogenic diet therapy for me is:	
	Over the past few weeks <b>it has helped when I</b> :	
	Today, my child's quality of life <b>score</b> is:  (circle a number between 1-10, where 1 is very bad and 10 is very	y good).

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# MY EVALUATION AFTER 3 MONTHS OF KETOGENIC DIETARY THERAPY

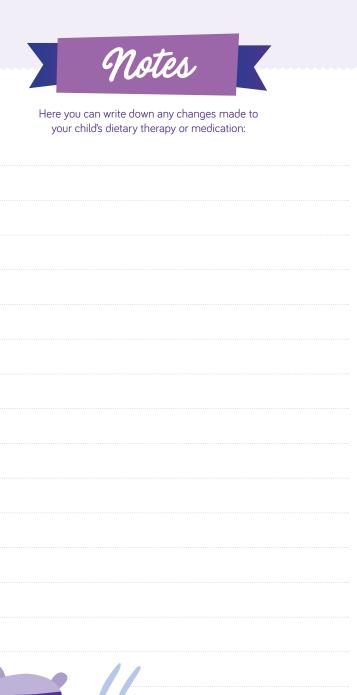


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My thoughts and feelings on ketogenic dietary therapy:	TEAM
When I look back at what my hopes were in the beginning	
to evaluate the experience of the ketogenic diet as follo	ows:
The total number of seizures that my child experiences about:	per week is currently
Type A: Type B: Type C: Type D:	Type E:
My child's quality of life scores now, as a result of the 3 mon (1 = very poor, 5 = very good)	th trial are:
✓ Epileptic seizures	1 2 3 4 5
✓ Physical (for instance pain, bowel movement, nausea)	1 2 3 4 5
✓ Social & emotional (for instance contact with others, mood)	1 2 3 4 5
✓ Behaviour (for instance passionate, cooperative)	1 2 3 4 5
✓ Cognitive (for instance alertness, speech/language, memory)	(1) (2) (3) (4) (5)









Here you can make a note of any questions you may have for your epilepsy team at your next appointment:





# Notes



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# Notes





