



# MY IgA NEPHROPATHY JOURNAL

## YOUR COMPANION BETWEEN APPOINTMENTS

[www.mykidneyhouse.co.uk](http://www.mykidneyhouse.co.uk)

### HOW TO USE THIS JOURNAL

This printable journal is intended for people with IgA nephropathy and those closest to them to complete and share with their healthcare team. It's designed to help make your life easier and can be adapted to suit your individual needs.

It has three sections:



#### Preparing for your appointments

Write down any questions or concerns so you can easily bring them up with your healthcare team at your next appointment.



#### Symptom tracker

Keep track of your symptoms to help your healthcare team understand how your condition is affecting your daily life.



#### My test results

Record your test results to keep track of your condition.

You have the freedom to print off as many pages as you need, based on your own health journey.

Print off as many pages as you need, and take them to your appointment.

**CSL Vifor**

This guide has been created by CSL Vifor for those who have been diagnosed with IgA Nephropathy

UK-NP-2500131  
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## PREPARING FOR APPOINTMENTS

Appointments with your healthcare team can be confusing, stressful and even overwhelming. It may help to spend some time thinking about any questions you'd like to ask before your appointment – that way you won't have to worry about trying to remember everything!

You might want to ask about things like:

### Questions to ask your healthcare team:



#### Your symptoms

- How can I manage my symptoms most effectively?
- What should I do if I have any new or unusual symptoms?
- How can I expect my symptoms to change over time?

#### Your diet and lifestyle

- Does my current diet support kidney health?
- How can I improve my diet to help manage my IgA nephropathy?
- Am I drinking enough water?
- Is there any food or drink I should avoid?
- Is alcohol safe?
- Can I do sports?
- Which exercises are safe?



#### Your mood

- Is it normal to feel anxious or depressed with IgA nephropathy?
- What lifestyle changes can I make to support my mental health?
- How can I take care of myself on difficult days?
- How can I access mental health support?



#### Your medications

- How do I take my medications correctly?
- What side effects can I expect?
- What should I do if I experience side effects?
- What should I do if I forget to take my medication?
- What should I do if I feel my medication isn't helping?



#### Things you don't understand

- What exactly is IgA nephropathy?
- What causes IgA nephropathy?
- Why do I feel so unwell with IgA nephropathy?
- Is there a cure for IgA nephropathy?
- Did I inherit IgA nephropathy from my parents?
- Can I pass IgA nephropathy on to my children?

Print off as many pages as you need, and take them to your appointment.







## TRACKING MY SYMPTOMS

It can be difficult to recall all your symptoms during a healthcare appointment, so you might find it helpful to record them in this journal instead. This can help your healthcare team see how your condition is affecting you from day to day, so it's worth taking the time to fill it in.

### How to fill in your symptom tracker

Use the following descriptions to help rate the severity of each of your symptoms, **0 being no symptoms at all and 3 being the most severe**. Record these in the printable symptom tracker on the next page. The symptoms listed below are experienced most often, but not everyone gets them. There is space for you to add any other symptoms you might experience. You can print as many copies as you need.

Physical symptoms	Severity	
 <b>Fatigue</b>	<b>0</b> None	
	<b>1</b> Mild	I need an early night but I'm able to get through my day without any problems
	<b>2</b> Moderate	I struggle to complete my usual tasks and cannot complete them to the usual standard
	<b>3</b> Severe	I am unable to function at all and cannot get out of bed, shower or brush my teeth
 <b>Swelling</b>	<b>0</b> None	
	<b>1</b> Mild	Someone who knows me well may notice a change in my appearance and there is mild discomfort
	<b>2</b> Moderate	I look obviously swollen to the people around me and feel some discomfort
	<b>3</b> Severe	I feel extremely self-conscious because of the swelling and am in a great deal of discomfort
 <b>Pain</b>	<b>0</b> None	
	<b>1</b> Mild	I sometimes notice minor pain, but can easily ignore it
	<b>2</b> Moderate	I notice a lot of pain, but I can still carry out other activities
	<b>3</b> Severe	The pain is unbearable and all I can think about
 <b>Brain fog</b>	<b>0</b> None	
	<b>1</b> Mild	I need to ask people to repeat things or reread things to take them in
	<b>2</b> Moderate	It's difficult to focus on my usual tasks and to process or express my thoughts
	<b>3</b> Severe	I am unable to function and I cannot think straight, concentrate or string a sentence together
 <b>Itching</b>	<b>0</b> None	
	<b>1</b> Mild	I have minor itching over parts of my body that can be easily ignored
	<b>2</b> Moderate	I have itching that is hard to ignore and causes skin discomfort
	<b>3</b> Severe	I have life-disrupting itching all over my body that results in damaged skin and pain from scratching so much
 <b>Insomnia</b>	<b>0</b> None	
	<b>1</b> Mild	I have difficulty falling asleep, but it eventually subsides and does not affect work or social functioning
	<b>2</b> Moderate	I have trouble getting to sleep or staying asleep, which can affect my social and work functioning
	<b>3</b> Severe	I have an inability to fall asleep unaided or stay asleep which has a major impact on my functioning during the day

Mood	Severity	
 <b>Anxiety</b>	<b>0</b> None	
	<b>1</b> Mild	
	<b>2</b> Moderate	
	<b>3</b> Severe	
 <b>Low mood</b>	<b>0</b> None	
	<b>1</b> Mild	
	<b>2</b> Moderate	
	<b>3</b> Severe	

Take this to your appointment along with your symptom tracker.

Print off as many pages as you need, and take them to your appointment.

# SYMPTOM TRACKER

Record which symptoms you have and their severity in the boxes of the calendar dates.  
E.g. on the 4<sup>th</sup>: 3 for Fatigue, 2 for Insomnia, 1 for Pain and so on.

Month .....

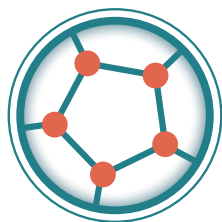


	Fatigue	Swelling	Pain	Brain fog	Anxiety	Low mood	Itching	Insomnia	Other symptoms
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31 <sup>st</sup>									
<b>If helpful, your healthcare team can work out your total score for the whole month for each symptom below</b>									
Total									

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## MY TEST RESULTS

Several tests are used to check how well your kidneys are working, but your doctor might focus mainly on:



### **Serum creatinine**

The level of creatinine in the blood is controlled by the kidneys. When the kidneys aren't working well, the creatinine level in the blood goes up. Serum creatinine is measured by blood test.



### **Protein in urine**

It's normal to have a very small amount of protein in our urine, however, when our kidneys are damaged, excess protein can leak through the filters. The result is foamy urine. Urinary protein is measured by urine test.



### **Glomerular filtration rate (GFR)**

GFR indicates how much blood is being filtered by your kidneys each minute, which also indicates how well your kidneys are working. Your GFR is based on your blood test results.

Use the table on the next page to record your test results along with the reference ranges from the lab. You can print as many copies as you need.

**The lab reference range is essential for interpreting your test results. It can change depending on which lab has processed your sample. Each and every test result must therefore be looked at in the context of the reference range that was used by the lab.**

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