

Living with
**IMMUNO
-SUPPRESSION**

THIS DIARY BELONGS TO

"STAY STRONG,
BELIEVE
IN YOUR STRENGTH,
NEVER GIVE UP"

-CIT.-

Chapter 1

my new KNOWLEDGE

Everything I'm learning
about kidney failure
and transplantation



Dear Diary, It's Elle here.

I'm having a bit of a tough week
and I kinda need someone to talk to.

As you know, my chronic kidney failure
is getting worse and my physician has been mentioning
that the best treatment for me would be to receive
a kidney transplant.

It's been a while since I felt well, between the poor appetite, the tired-
ness and the headaches...

Yesterday, during the dialysis session, my doctor and me, we went
again over how this is my best option...

**AND POSSIBLY THE ONLY CHANCE I HAVE
FOR A BETTER AND LONGER LIFE.**

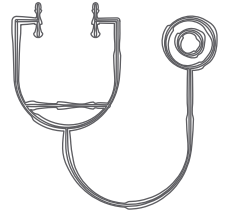
I'm not gonna lie, I am scared.
But at the same time, I also feel
strong and determined, ready to fight.

I have no idea how such conflicting emotions can be felt
at the same time.

I have so many questions in my head and right now,
I don't know how I'm feeling.

Anyway,

Dr. Nichols has been so caring and helpful;
he gave me all the details, information and advice
I will need to face what is coming.
I'm so grateful for his patience.



→ But where do I begin?

There's so much I want to tell you and take note of,
you know better than anyone else how meticulous I am!
I hope writing can help me feel more in control.

So let's start from the basics, deepen the topic and try to find an answer
to all my questions!

FROM NOW ON,
I WILL SHARE
WITH YOU,
MY DEAR FRIEND,
EVERYTHING
I AM LEARNING
ABOUT MY CONDITION.

How do kidneys work?

First things first.

What do kidneys do? And what do they look like?

I didn't know anything about it and since I'm so bad at biology, I asked the physician to explain it as if I were a child.

Sounds weird, having something for all of your life and never knowing how it works, at least until it starts acting up, right?

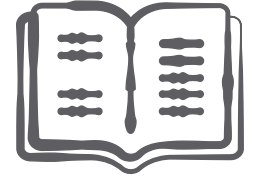
First of all, kidneys are busy doing a lot of things for us, and we all need at least one of them to live!

They are two bean-shaped organs located on the lower back, on the sides of the spinal column.



THEY ARE ABOUT THE SIZE OF A FIST

THE KIDNEYS DO A LOT AND THEY DEAL WITH NUMEROUS FUNCTIONS, INCLUDING:

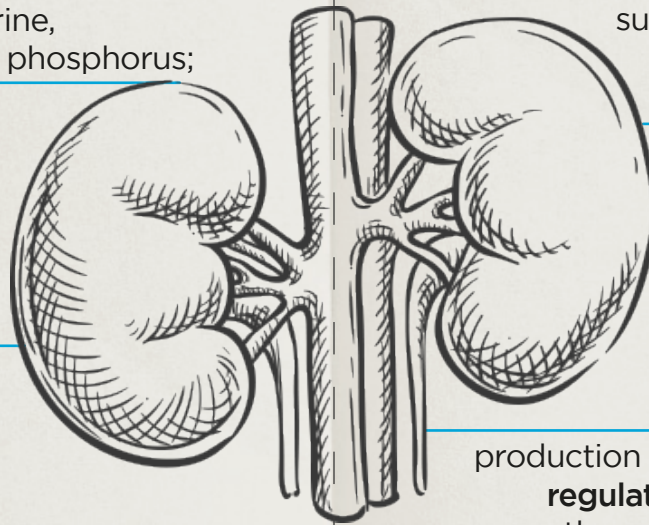


correct levels of minerals in the blood, such as calcium, sodium, potassium, chlorine, magnesium and phosphorus;

they filter the blood, eliminating any waste or any potentially toxic substance they find through the urine they produce;

the body's water balance;

production of hormones that regulate blood pressure or the amount of red cells in the blood.



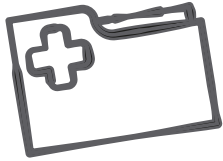
FUNCTIONS of the **KIDNEYS**

NOTES:

KNOWING AND UNDERSTANDING

helps to live through the therapeutic path in a more peaceful way.

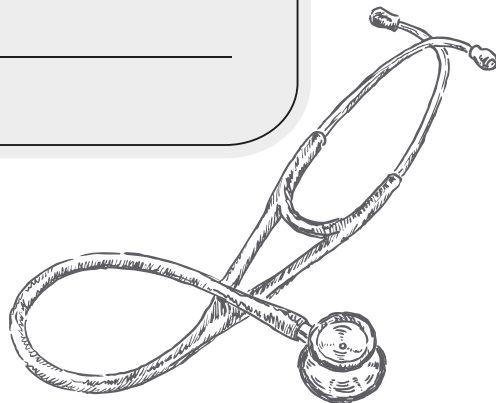
kidney failure



When I first had symptoms, I had zero knowledge of what was happening to my body. I had no idea of why I always had this sense of fatigue and of being very cold...

...only much later I found out what kidney failure is.

* MY SYMPTOMS



WHAT HAPPENS TO THE BODY OF A PERSON WHO, LIKE ME, EXPERIENCES KIDNEY FAILURE?

Basically, when kidneys stop performing their functions, like removing waste and extra water from the blood or keeping body chemicals in balance, that is kidney failure.

Kidney failure can be temporary or permanent, and without treatment the damage can only get worse.



This condition is divided into:

ACUTE

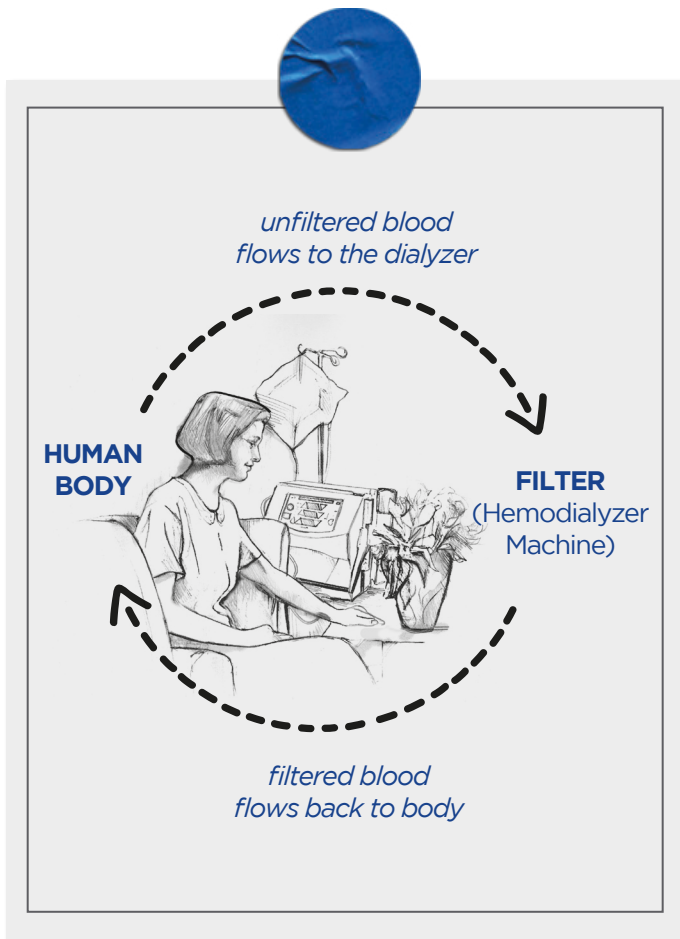
Acute kidney failure generally occurs suddenly **and is often reversible.**

CHRONIC

As for the chronic type, however, the failure **develops over a long period** and you might end up needing dialysis or, like me, a kidney transplant.

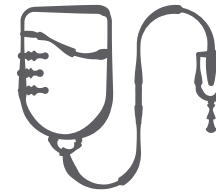
Why do I need dialysis?

SINCE MY KIDNEYS
HAVE STOPPED WORKING PROPERLY,
DIALYSIS HAS BEEN HELPING ME
KEEP MY BODY FUNCTIONING
AS NORMALLY AS POSSIBLE.



How it works
is actually quite simple:
this treatment
filters and purifies
the blood
using a machine
(I know that it sounds
a little bit gross,
but it is what it is),
and it's essentially
an artificial method
of replacing
renal function.

In a nutshell, Dr. Nichols told me that, without dialysis, waste products and extra fluid can build up to dangerous levels in my body, causing a number of unpleasant symptoms and damaging other organs.



SO YES,
DIALYSIS IS NOT FUN AT ALL
BUT FOR THE MOMENT
IT'S MY LIFELINE.

I feel a bit tired while doing dialysis,
and sometimes even soon after I have finished the treatment.
My medical team, however, told me that this is completely normal
and that they are always there for me.

Here's another thing I've learned. There are two main types of dialysis:

HEMODIALYSIS AND PERITONEAL DIALYSIS.

The biggest difference between the two is that

with the first one
the blood is transferred
from the body
to an artificial kidney
which filters it.

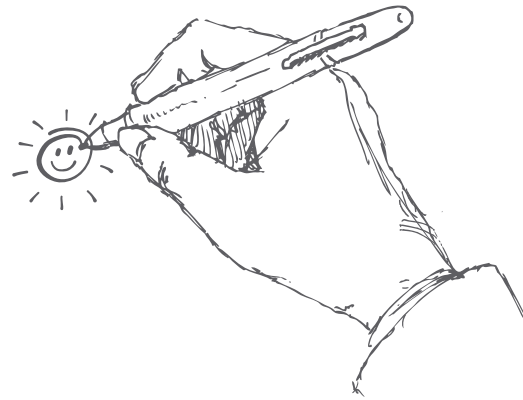
While, in the second one,
on the other hand,
the patient's peritoneum*
is used as a filter.

*IT'S A SHEET OF TISSUE
THAT SURROUNDS
MY ABDOMINAL ORGANS

PRETTY CRAZY, RIGHT?



Dear Diary,
Today was a great day!



I can't say I feel my best but I definitely feel that I'm going in the right direction.

This morning I had a meeting with Dr. Nichols and the care team to learn about what is involved in transplant surgery.

They told me everything I needed to know and gave me a bunch of documents to read, and I must say,

I AM KINDA GETTING USED TO MY

"LEARNING MATERIALS"



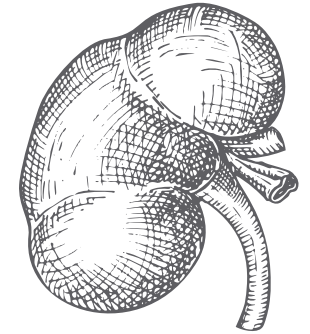
The whole team is simply great.

They always encourage me to raise any questions I have above

- kidney disease,
- transplantation,
- and the treatments involved.

In the beginning,

I was a little afraid to express my doubts and concerns, but then I thought maybe the experience of a physician could have been helpful for educating myself



I might still get scared sometimes, but there is a whole team looking out for me, so I'm doing my best to trust them! At least,

THAT'S HOW I FEEL...

overall,

I'M STARTING TO FEEL BETTER AND I AM FEELING EMPOWERED BY WORKING WITH MY CARE TEAM.

I JUST CAN'T WAIT TO START A NEW CHAPTER IN MY LIFE.

But for now, all I can do is trust the doctors and follow their advice regarding fluid, diet and exercise. I also want to learn as much as I can about transplants, rejection, and immunosuppressive therapy.

What is a kidney transplant?

A kidney transplant is an operation that places a healthy kidney in my body that does the work my own kidneys can no longer do.

(UNFORTUNATELY)

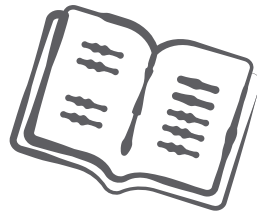
RENAL TRANSPLANTATION

is considered the best solution for end-stage renal failure patients when appropriate.

IT OFFERS A BETTER QUALITY OF LIFE AND BETTER LONG-TERM HEALTH.

The first thing that I've learned about this treatment is that a successful transplant depends on certain factors, like:

- a good overall health
- a good kidney donor match.



BUT WHAT DOES THIS ENTAIL?

First of all, before starting the process, it's necessary to undergo a **series of tests**, that include checking for the presence of any diseases incompatible with the transplant or with the drugs I need to be taking after surgery.

THE JOURNEY

The outcome of the tests will determine whether I'm suitable for transplantation and can be placed on the waiting list.

This match is really essential because it helps to lower the risk of rejection.

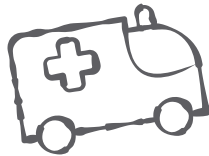
In the case where a living donor is available, that person also undergoes a series of tests to ensure that they are suitable as donors and have all the prerequisites to live a long and healthy life with only one kidney.

Once on the waiting list, I will have to, well, wait until a kidney that has a **good "compatibility"** with me will be available. That means that the new kidney must be from a donor who has the **same tissue type** and a **compatible blood type.**

What is, and what happens during kidney rejection?

Here comes the part that scares me the most.

REJECTION



Rejection is the body's way of not accepting the kidney transplant.

THE IMMUNE SYSTEM
RECOGNIZES THE TRANSPLANTED ORGAN AS A FOREIGN BODY AND ATTACKS IT, USING DIFFERENT TYPES OF MECHANISMS, JUST AS IT WOULD ATTACK ANY INFECTION OR BAD COUGH.

The greater the compatibility between the new kidney and myself, the lower the possibility of encountering rejection.

Immunosuppressive drugs help in preventing rejection, but we'll talk more about that later. one thing at a time...

Although rejection is most common **in the first months after surgery**, it can occur at any time and these are some of the most **common symptoms**:

- Fever and reduced urine output
- Elevated blood creatinine level
- Protein in the urine

If any of these symptoms occur, the first thing to do is to contact the transplant team immediately so they can treat the episode and give me all the support I need.

However, the only thing I can check myself is the fever, while the other symptoms are found either via blood or urine samples.

I better get one of those digital thermometers at the pharmacy!

★ I REALLY HOPE TO TELL YOU AS SOON AS POSSIBLE THAT A NEW KIDNEY FOR ME HAS BEEN FOUND! ★



Dear Diary,
It's been a while.

BUT I'M COMING TO YOU NOW WITH
A BIG SMILE ON MY FACE.

I finally got my new kidney
and can't find the words to express

HOW HAPPY AND GRATEFUL I AM.

So many changes and emotions have filled
the last months....



Getting a kidney transplant feels like

I'M GETTING ANOTHER CHANCE AT LIFE.

And there are so many great things that I can enjoy again,
I'm no longer on a renal diet or fluid restriction.
The fatigue is more or less gone, I have so much more strength now.

For the first time in forever I feel well rested when I wake up.
I'm looking forward to having more freedom
and time to spend with my friends
and family.

on the other hand,
however, I also need to consider
numerous new aspects in my after-transplant life
that mainly concern the care of my new kidney.



LIST OF THINGS
TO BE GRATEFUL FOR:

In that regard, have you ever heard of
immunosuppressive drugs?

Why are immunosuppressants used for kidney transplant?

YOU ALREADY KNOW ABOUT REJECTION, DON'T YOU?



Well, one risk of a kidney transplant is that my body's immune system may mistake my new kidney for a pathogen or something that may harm me. Long story short, it is possible that my immune system may attack my new kidney as part of its normal response to a foreign body.

After the transplant, I will have to pay attention to what my transplant consultant will tell me on my medications.

The immunosuppressive drugs will prevent my immune system from attacking my new kidney, but at the same time it must still have the ability to fight infections, bacteria and anything else that may be harmful.

Balancing my medication can be one of the most challenging parts of looking after me after my transplant.

IMMUNOSUPPRESSANTS ARE VERY POWERFUL AND NECESSARY DRUGS, RESPONSIBLE FOR KEEPING THE NEW KIDNEY HEALTHY AND WORKING.

(AS DR. NICHOLS SPECIFIED)

It is important to take my immunosuppressants and other medicines exactly the time and way he told me to.

I have to be careful with my meds, as my doctor said skipping them can really hurt my kidney ...and I don't want to risk losing it. I need to take care of it.

I also got in touch with a transplanted patient via the hospital, who suggested that I get one of those pill organizers and an app to download on my phone to remind me when to take my meds. The app can even remind me to bring my medicine when I get out.

HOW DID WE MANAGE TO LIVE WITHOUT THESE APPS?

NEXT CHECK PAGE!



Anti-rejection medicines also come with **risks and side effects** which vary depending on the type used

SO IT'S IMPORTANT TO BE PREPARED TO DEAL WITH THEM.

LAST BUT NOT LEAST, I LEARNED THAT

immunosuppressive therapy is divided into:

INDUCTION THERAPY

intense immunosuppression with immediate effect, to prevent acute rejection. This is something that I will go through in **the period around the surgical procedure.**

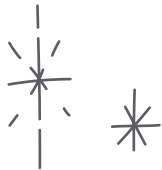
MAINTENANCE THERAPY

immunosuppression to prevent rejection over time, necessary throughout the post-transplant period. This is going to be my **life-long companion**, so that my new kidney will be my life-long companion too.



This is a letter

I have received from another patient regarding their journey



I WILL TREASURE IT DEARLY



I was transplanted at the age of 68.

It was done over the "blood group" project, which means my blood did not match my living donor; I am O positive and they are B.

This is a special "one of a kind" project that is done at a university hospital.

At the age of 64, I was diagnosed with kidney disease when my kidney function was rapidly declining. After testing my kidneys, it showed the cause could have been high blood pressure.

The search for a new kidney was done with various family members and friends who came forward. Ultimately, it was decided after various tests my partner would go into the program.

She and I had the same tissue match.

I suffered renal failure early that year after contracting a terrible flu and began to swell on my extremities and literally sat up sleeping after not being able to breathe. I went to the hospital and was put immediately on dialysis for 3 three months.

At the same time active blood test were being done on my donor and they discovered she had a non-cancerous tumor on her liver.

(When a patient has cancer or has undergone cancer treatments, they are taken off the list to donate). After establishing her tumor was benign, we were able to move forward with my transplant.

When you are admitted onto dialysis, the Kidney foundation puts you on the list for a donor in the country. Statistically it shows that the wait is 5 years for a donor in our country.

Dialysis is the "band aid" for kidney disease, and does the function of your damaged kidney—which is cleaning the blood. This procedure is very taxing on your body and after dialysis your body feels "beaten up" and you require rest. The following day you do have energy but that is short-lived and you are on your way to the next treatment which is done 3 x per week.

As I explained earlier, I was most fortunate to have my donor test positive for the same tissue match.

This meant before the planned operation, I had to undergo every day for three weeks a special dialysis treatment; where two machines together would take out all my antibodies so that my body would not reject her kidney.

This machine, I call it the "miracle machine". However, this was no guarantee once the transplant took place that there would be no rejection. Many things can happen.

The day I was admitted into hospital, this procedure continued until that afternoon when the nephrologist gave the go ahead for the operation based on my correct anti-body levels.

A note: most people don't know this but, I gained an additional kidney, my damaged kidneys are never removed.

The next day I was ready to have my operation. I was excited and I nervous more for my donor who is my partner. After early morning meditation we were both hopeful and had a lot of faith in the "kidney team". She went in first and then they prepared me to go in 4 hours after.

I remember waking up and asking how she was... They then wheeled me into my room and few hours after I was very hungry and asked for a salmon meal. Totally Crazy!!

My donor who had never undergone any operation, was slow to wake up but she was later wheeled to her room and I saw her the following day. We were placed in two different areas of the transplant ward and the reason for this, is so that we would not be overly concerned and focused on how the other was healing.

I was going to feel one hundred percent better than before and she not at all. She was the donor and an organ was taken out of her body--- I call a kidney donor "A hero" The ultimate sacrifice a human does to help another human being.

You see, I woke up feeling energetic after years of having no energy and feeling sick after dialysis treatments. My new kidney began to work immediately on the operation table.

My "second life" began the moment I received my new kidney; I was allowed to see it when an echo was done. For me this is a scientific wonder and I named her "Sun Flower".

For the 9 days I remained in the hospital the "transplant team" visited me daily and observed my progress and how much urine I produced, incidentally it was quite a lot as described by the nurses.

I was informed how to take my medication on time and tips how to prepare them for the week. I had to be extremely careful which foods not to eat and certain fruits and herbs I was never to take such as; grape-

fruit and St. John's worth which can affect the medications working properly.

I remember when I was being released, a very kind nurse said to me, "you have done well, don't let me see you back here because you forgot to take your medicines". I never forgot that.

I could eat everything but to stay specifically away from uncooked or raw foods, "street foods", pates, raw fish and foods basically that were not cooked well.

My salt should be minimized and to be sure that I drank enough water at least 1.5-2 liters per day. You don't want to overdo it since that can present its' own problems.

I was anxious to get back to exercising and travelling, but I was advised by the "team" not to do any contact sports and be careful in settings with low hygiene.

When I travelled, I had to be sure to take my medications at a specific time which can prove challenging if you are travelling to a different time zone. Very important, taking your medication on time is key to no rejection.

I am a vegetarian, and I felt eating no red meat helped my new kidney. I make sure I exercise at least 3 x per week, whether it's walking outside or on my App at home. I am a Buddhist and I actively meditate daily.

Yes, it is true that the medication we take in particular can induce diabetes and this presents other challenges but nothing that cannot be overcome by the right doses of insulin, medication and exercising is the key. Walking daily or exercising at least 30 minutes or more

per day and eating the right foods can do wonders for keeping your diabetes in control.

I feel that by doing everything possible to live healthy is definitely in my hands which gives me a second chance to live a normal life again.

To date, I am going into my fifth year with my new kidney and every four (4) months I am monitored by the "transplant team", a group of professionals that I can talk to easily about any concerns I have about my health.

I am very happy to say that my new kidney has stabilized and I am able to enjoy my passion – travelling.

My motto; "do not put anything off for another day but live without fear and live sensibly. Tomorrow is not promised.

Thanks to this wonderful project "over the blood group" and my generous donor. I'm forever grateful!!

Bernadette

Well,
I guess that's it
for now.



As I sit in my comfy chair and write this,
Marley is asleep by my feet and outside
the sun has just come out



- I think I'll go for a walk!



I FEEL SO GLAD RIGHT NOW TO BE HERE
AND, WITH THE HELP OF ALL MY LOVED ONES,
I TRULY BELIEVE I CAN DO THIS.

Thank you for listening my dear friend,
I'll keep you posted.

love,
Elle

Suggested readings

SPECIALIZED ARTICLES:

- **Minetti E. Il trapianto renale nell'anziano.**

Giornale Italiano di Nefrologia. September - October 2019, a. 36, vol. S72, pp 118-123.

IN-DEPTH ARTICLES:

- **Il Rene, la Dialisi, il Trapianto.**

Available at <https://www.progettoalice-seu.org/sindrome-emolitico-uremica/rene-dialisi-trapianto.html>.

Date accessed: 09 January 2023.

- **Caratteristiche generali della dialisi.**

Available at <http://emodializzati.it/dialisi/>.

Date accessed: 09 January 2023.

- **Rigetto acuto e cronico.**

Available at <https://www.issalute.it/index.php/la-salute-dalla-a-alla-z-menu/r/rigetto-acuto-e-cronico>.

Date accessed: 09 January 2023.

- **Che cos'è il trapianto di rene.**

Download available at <https://www.maggioreosp.novara.it/che-cose-il-trapianto-di-rene/>.

Date accessed: 09 January 2023.

- **Un bene prezioso da tutelare.**

Download available at: <https://www.aovr.veneto.it/documets/20182/31037/un-bene-prezioso-da-tutelare.pdf/8e23c662-f454-4ea1-856c-a71bb5cb3c7b>.

Date accessed: 09 January 2023.

- **La vita continua! Guida informativa per i pazienti in attesa di e con trapianto renale.**

Download available at: https://www.asst-settelaghi.it/documets/41522/2486281/0654_15X-OPUSCOLO10x21.pdf/45ad9e93-35bb-0cd3-3784-ad670a518707.

Date accessed: 09 January 2023.

"THE TWO MOST
POWERFUL WARRIORS
ARE PATIENCE AND TIME"

- LEV TOLSTOJ -

Chapter 2

my new **ROUTINE**

How I've embraced
my brand new
post-transplant life

WOW! Dear Diary, What a month it has been!

I cannot begin to tell you how much I appreciate everyone's love and care. I am honestly overwhelmed with the support I have received so far.



AND A SPECIAL THANKS CERTAINLY GOES TO ALL THE MEDICAL TEAM WHO ASSISTED ME DURING THE TRANSPLANT;

I have really received attentive and thoughtful care, from both doctors and nurses.

I feel like I can understand what they were telling me:

after the transplant,
I feel I have a new lease of life,
and that endless opportunities are ahead of me.

But this new beginning also means, at least for me, learning to face a variety of new challenges.

They told me at the hospital
how essential it is for the success of the transplant:

to be as adherent as I can to what my doctor advised and prescribed, especially to **prevent rejection or complications** and to **facilitate the body's adaptation** to the new condition.

➔ For this reason, every day I have to take multiple medications, follow different instructions and be sure of putting into practice the recommendations received relating to daily life and lifestyle.



e.g.

- nutrition,
- physical exercise but avoiding heavy lifting,
- hygiene,
- behavior measures aimed at preventing infections, etc.

SOMETIMES I FEEL IT'S HARD TO KEEP EVERYTHING STRAIGHT

Let me tell you, I have been very scatter brained and found it difficult to concentrate for some time post-transplant.

You know, kidney failure has implications on my cognitive functions. I remember I had such a hard time handling complex thoughts prior to the transplantation, but this was so much easier even only a few days after!

However, there are a number of things I can do to get organized and remind myself to take all drugs.

How to simplify the "timed" drug therapy:

- Get a pill organizer, a container with the days of the week to keep my medication for the week ahead
- Set reminders or alarms on mobile phone/digital watches
- Place post-its in strategic places in the house
- Outline the drugs to be taken on the calendar
- Follow a step-by-step daily routine
- Keep extra medicines in your bag or your car in case something unplanned happens and you do not get home in time

There are also apps that "escalate" and increase the **intensity of the alarm** when you disregard it, or other apps that can **remind you to bring your pills** when you leave home or even contact someone else if you haven't turned off the alarm by **stating that you have taken your meds.**

FRIDGE SHOULD WORK!

NOTE TO SELF:

TAKE IMMUNOSUPPRESSANTS AND ANY OTHER DRUGS AS DIRECTED BY THE PHYSICIAN!

Not taking them the correct way can:

- Expose me to greater risks
- Lead to more hospital visits
- Cause a rejection episode

Things I've learned this month:

- 1. I must find in myself and in my own personal, family and relationship context, the strength to face my path
- 2. Being motivated and having a positive and optimistic attitude can help me to take all the next future steps with serenity and patience.
- 3. Take it one day at a time

→ I WON'T FORGET THE PAST, BUT AM THANKFUL FOR THE NEW LEASE OF LIFE I NOW HAVE.

Easy and practical ways to remind myself of check-ups and medical examinations:

- Use a journal to **record all the exams** and visits booked or to be booked
- **Set up reminders** to book and to go to prescribed exams and visits
- Don't be shy to **ask for help** if I feel I need it! Family members or loved ones can help remembering appointments
- **Write down any questions** I may have so I won't forget on the day I meet my doctor

→ MY COUSIN SARAH WOULD BE GREAT FOR THIS TASK!

NOTE TO SELF:

DON'T BE AFRAID TO SHARE WITH MY DOCTOR OR MY NURSE ANY DOUBT, FEAR, OBJECTIVE OR SUPPOSED DIFFICULTY RELATING TO THE THERAPEUTIC PATH.

The single most important step you can take is to ask the whole care team for help to receive the necessary information and/or identify what could work for you

Dear Diary,
There have been ups and downs
over the last period.



My friend Jim, who is a psychologist,
told me yesterday that it is ok to feel a rollercoaster of emotions.
Having a kidney transplant is not "just" a physical experience,
but it is also an emotional one.

... that it is so true!

I must say, however, that I have found some ways to:



TAKE CARE OF MYSELF, TO SWITCH OFF AND RELAX
NO WORRIES OR CONCERNS
KEEP ONLY POSITIVE VIBES AND GOOD THOUGHTS



Here's what I like to do!

BREATHE FRESH AIR!
TAKING A WALK EVERY DAY
IN THE PARK IS A REAL CURE-ALL



JOINING A SUPPORT GROUP
(WHICH IS WHERE I MET JIM!)



MEDITATING TO MANAGE STRESS AND DOWN MOMENTS...
THIS HAS HELPED ME TO UNDERSTAND
WHAT IT MEANS FOR ME AND HOW TO BE GRATEFUL
AND THANKFUL AFTER RECEIVING MY KIDNEY



TAKING CARE OF MY ROSES



GETTING A MASSAGE WHENEVER I CAN
(I CONFESS, THIS MY FAVORITE ACTIVITY)



TRYING SOMETHING NEW EVERY
TIME I GET THE CHANCE

Do away with fatal thoughts or negative thinking.
Stay away from people with gloom and doom.
Build Faith in yourself! Super important!

Drug therapy, medical examinations, and check-ups:

OH BOY, HOW MUCH MY EVERYDAY LIFE
HAS CHANGED!

But fortunately,
these are all positive changes
that I am getting used to
little by little.

Lists and post-its have been helpful in making easier
to keep in mind all the things to do and to adapt to this new routine.
Phone apps and an extra supply of medicines in my car have already
helped me a couple of times!

All right, now I really have to go, but I still have a lot of things I want
to tell you; for example, you already know Dr. Nichols but you don't
know anything about the care team yet.
They are all so nice and kind!

Next time I'll tell you all about it!
Will be writing again soon.
Elle

Suggested readings

SPECIALIZED ARTICLES:

- **Cartabellotta A. La non-compliance alla terapia farmacologica: strategie diagnostico-terapeutiche.**
Evidence 2013;5(7). e1000051. doi: 10.4470/E1000051.
- **Federazione Ordine Farmacisti Italiani. Linee Guida per una migliore adesione alle terapie farmacologiche.**
Documento a cura del comitato centrale FOFI (2015/2018).
- **Horne R, Weinman J. Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness.**
J Psychosom Res. 1999 Dec;47(6):555-67.
- **Manifesto per l'aderenza alla terapia farmacologica sul territorio italiano,**
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- **Miller W, Rollnick S. Motivational interviewing.**
New York, Guilford Press, 1991. Copyright © 1992 John Wiley & Sons, Ltd.
- **World Health Organization. Adherence to long-term therapies: evidence for action,**
2003.

IN-DEPTH ARTICLES:

- **Holiday / travel vaccinations in transplant patients - National Kidney Federation.**
Available at: <https://www.kidney.org.uk/holiday-travel-vaccinations-in-transplant-patients>.
Date accessed: 13 March 2023.

"ANYTHING IS POSSIBLE
WITH THE
RIGHT PEOPLE THERE
TO SUPPORT YOU."

-CIT.-

Chapter 3

my new **FRIENDS**

How my care team
is helping me through
each day

Dear Diary,

today I want to introduce you
my new friends,

the ones who hold my hand along my journey
with all its ups and downs.

I GUESS YOU'RE WONDERING
WHO THESE NEW FRIENDS ARE...

They are the care team members
who are helping me daily to improve adherence and management
of my therapeutic path.

I want to be honest with you.

At the very beginning I was scared of physicians as I've always thought
of them as very judgmental people, with little empathy.

Well, throughout this journey I'm on, I've seen a very different side
and realize now I was completely wrong.

They always guide and support me
through my therapeutic path and always there to listen
when I ask for help. I feel free to discuss with them every
aspect of my condition.

THIS HELPS ME CLEAR ANY DOUBTS OR WORRIES,
SO I CAN DISCUSS HOW MY FUTURE MAY LOOK.

During the first visits I was shy and I wasn't confident enough
to ask a lot of questions.

Nevertheless, they always did their best to make me feel comfortable
so now I'm happy to

TALK WITH THEM OPENLY

AND WITHOUT FEAR
OF BEING JUDGED.

*REMEMBER:

EVEN AN APPARENTLY

UNUSUAL TOPIC

COULD BE COMMON

NOTE TO SELF:

THERE ARE NO
TABOO ARGUMENTS
WITH MY PHYSICIANS!
I CAN TALK ABOUT
WHATEVER I WANT
WITH THEM!

... and already present
in the experience of the physician,
who probably already has
the tools to help me deal with it.



Dear Diary,

Today I want to talk to you about a very important issue:

follow-up visits.

When my check-ups started, I wasn't completely aware of their importance.

Now I know that they represent a fundamental moment in which I can bring my own situation, questions, expectations, and fears to the physician's attention.

I AM VERY PROUD OF
HOW I AM FACING THESE VISITS!

A lot of things can influence how a follow-up visit can go, like:

- a period of stress due to tight deadlines,
- rushing,
- or simply being a bit forgetful due to all of the emotions.

(BEEN [^]THERE!)

What to do then?

I try to prepare in advance to avoid missing out any relevant issue or problem I want to discuss.

In fact, a visit is a moment that cannot be improvised: it requires the right preparation in order to make optimal use of the time available for discussion with the care and support team.

A good preparation can help in approaching the visit itself and all the therapeutic journey in the safest and most relaxed way.

(REASONABLY!)

Here the most important things that I've learnt in this period about how to get ready for my follow-up visits and take the best from them.



CHECK
NEXT PAGE!



BEFORE THE VISIT

1.

Keep an agenda or use a diary

to record the dates of the check-ups and organize the commitments in such a way as to be available for the appointed day.

(e.g. free yourself from other activities, assess the need to be accompanied by third parties, etc.)

Remember to **take your immunosuppressive medications the day of the visit**, especially if a blood withdrawal is planned.

2.

This will help correctly assessing the levels of the immunosuppressive drugs in case an adjustment is needed

3.

Check whether lab tests or instrumental tests to undergo before the visit have been requested:

obtain the necessary documents for the examinations.

Make the appropriate reservations and undergo the investigations in advance, in order to have the reports available for the day of follow-up visit.

4.

Make sure to have **all the necessary documents for the follow-up visit**, otherwise get them in advance;

check the methods of acceptance of the facility where the visit will take place (e.g. admission times).

If there are unforeseen events that make it impossible to show up for the appointment on the day or time established, **inform the health facility and ask to make a new appointment.**

5.

Life is unpredictable!

6.

Record any observation, concern or question

in the Program Diary.

Last but not least: if possible, **have a family member or loved one accompany to the visit**

7.

to feel more comfortable and supported in remembering important issues.

DURING THE VISIT

1.

Wear comfortable clothes

that facilitate the follow-up visit.

Bring the list of drugs taken, the documentation relating to previous checks and visits, **the reports** relating to instrumental and lab tests that have been requested,

2.

and any reports of visits or tests carried out in the meantime with other specialists.

3.

With the help of the Diary, **discuss with the physician everything that was previously noted in relation to any symptoms** that have been felt or are still felt:

have new symptoms appeared?

How long have they been showing up?

Are they always there or do they come and go?

Is there something that makes them get better or worse?

What impact do they have on daily life (working capacity, social life,...)?

Is there any remedy to get some relief?

What do these symptoms mean in the context of the condition?

4.

Do not be afraid to ask for information on the results of the tests undergone and, if further investigations are required, **feel free to ask** why other tests are needed,

how and where to perform them, what significance or importance will have the result

Talk to the physician about the therapy: are there any difficulties or are there particular aspects that create problems?

5.

If necessary, ask for further clarifications on the therapy and its purposes, raise any concerns and do not be afraid to ask if there are alternative therapies

6.

If new drugs are prescribed, **make sure to have understood the reason for the prescription, the correct dosage and method of administration,**

any expected side effects and their management.

Discuss areas of concern with the physician

7.

do not be afraid to raise concerns about health and future.

8.

Freely explain any other difficulties encountered and ask for support in relation to other aspects of managing the condition

(nutrition, exercise, sleep quality, social and relationship life, sexuality, social rights, etc.)

Write down any advice or suggestion received in the Program Diary.

9.

In case you feel something is not clear enough, feel free to ask the physician to explain in an easier way or to repeat without using a technical language.

10.

Ask the physician if there are contacts which can be used, in case it is necessary to speak to the Clinical Center.

even after the visit!

I KNOW THAT CAN SEEM TOO MUCH STUFF TO DEAL WITH BUT NOW I CAN SAY THAT I CAN DO IT.

The most important thing not to feel overwhelmed

IS TO TAKE ONE STEP AT A TIME, TRYING TO BE

POSITIVE ABOUT THE FUTURE.

Everyone has their own path but is important to take it seriously and do our best to make things work!

I think I've said enough for today.

love,
Elle



Suggested readings

SPECIALIZED ARTICLES:

- Gentili, P. (2002). Come prendersi cura del malato cronico. Roma: CISU.

- Paris, V., Fiorini, F. Psicologia della comunicazione tra medico/infermiere e paziente in nefrologia e dialisi.

G Ital Nefrol 2019 - ISSN 1724-5990 - Anno 36 Volume 4 n° 2.

" IT IS DURING
OUR DARKEST MOMENTS
THAT WE MUST FOCUS
TO SEE THE LIGHT."

- ARISTOTLE -

Chapter 4

my new CHALLENGES

Possible post-transplant events
that I may need
to be ready for

Dear Diary,

Today I want to talk to you with

I NEED TO. ⁷ an open heart.

A lot of people think that after the transplant everything is gonna be ok immediately, but it's completely normal to feel bewildered and with ups and downs.

ALL BIG CHANGES REQUIRE SOME TIME TO GET USED TO, AND IT'S PERFECTLY NORMAL...

After the transplant, I started following all measures and precautions indicated by the care team:

- follow the instructions they gave me
- learn about what to pay particular attention to
- always be aware that even though I'm now feeling much better, there are certain things I need to be careful about, more than i used to in the past

It's easy to feel different than before, or maybe to feel worried or isolated from other people due to the fear of contracting infections or of skipping your meds.

This whole situation can become stressful, generating severe worry or depression.

I've been worried and stressed for a while and I talked about my feelings with the care team.



I DO THIS IN ORDER TO RECEIVE THE NECESSARY REASSURANCE.

This helps to plan together the correct steps for me to restore my state of emotional well-being.

NOTE TO SELF:

IT'S OK TO NOT BE OK.

So I can finally find a balance despite all the challenges I have to deal with.

It's these challenges I want to talk to you about now.

Check-ups and other specialist visits

After discharge,
a specific clinic of the Transplant Center deals with my continuation
of the therapeutic path and I can contact them for any need.

Follow-up visits
(MORE FREQUENT AT THE BEGINNING
AND LESS FREQUENTLY THEREAFTER)

go along with ↓

blood samples - urine tests - diagnostic control tests
(WHICH ARE DISCUSSED IN DEPTH
DURING THE MEDICAL EXAMINATION.)

As I said many times,
it is important to carefully respect the frequency of the checks
and always ensure to be adequately organized to undergo the necessary tests.

Remember to undergo
an ophthalmic and a dermatological examination
every year to check the condition of the skin.

Infections

Transplant recipients like me may have an increased risk of getting
infections due to immunosuppressive anti-rejection therapy.

Some infections can happen due to

THE REACTIVATION OF INFECTIONS OF VIRUSES

or bacteria that have
remained latent
in the recipient
(think for example
of the varicella virus)

WHILE OTHERS CAN
BE CONTRACTED
DIRECTLY
after transplantation.

SOME INFECTIONS CAN EVEN BE TRANSMITTED

directly together
with the transplanted
organ
(donor infections).

For this reason it is important to undergo any antibiotic prophylaxis
prescribed immediately after the transplant and to follow it carefully
for the period indicated by the doctor.

NOTE TO SELF:

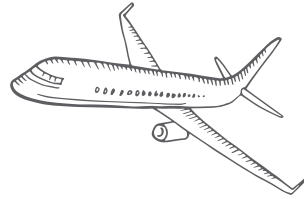
IT'S BETTER TO CALL
THE CARE TIME
ONE TIME MORE
THAN ONE LESS.

USEFUL NUMBERS:



Three horizontal lines for writing useful numbers.

Vaccinations



Before undergoing any type of vaccination, it is important that I discuss this with the doctor, to receive safe and suitable information for my specific case.



Immunosuppressive therapy, by regulating the activity of the immune system, can theoretically make vaccinations less effective.

Some specific vaccinations can even be harmful like in the case of "live vaccines" such as the yellow fever.



I SHOULD REMEMBER TO DISCUSS MY FUTURE TRAVELS WITH THE CARE TEAM!

Possible signs of organ rejection

Although immunosuppressive therapy is prescribed in order to avoid rejection phenomena, some apparently alarming episodes may occur.

However, if promptly reported to the doctor or the nurse, these can be resolved, for example by adjusting the dosage of the drugs already in use.

It is always good to contact the care team and report any suspicious symptoms that have recently appeared such as:

REDNESS HEAT OR CHILLS	DIFFICULTIES FOLLOWING MINIMAL EFFORT	PAIN OR TENSION IN THE TRANSPLANTED KIDNEY
FEVER EQUAL TO/HIGHER THAN 38°C	NAUSEA OR VOMITING	24-HOUR WEIGHT GAIN
GENERAL MALAISE AND WEAKNESS ASSOCIATED WITH MILD FEVER	HEADACHE OR DIZZINESS	SWELLING OF THE FEET AND ANKLES
SHORTNESS OF BREATH OR BREATHING	GENERAL SENSATION OF PAIN	REDUCED URINE PRODUCTION IN 24 HOURS
	PAIN OR TENSION IN THE TRANSPLANTED KIDNEY	INCREASE IN BLOOD PRESSURE

Diabetes

SOME ANTI-REJECTION DRUGS CAN INDUCE DIABETES.

If this condition should happen to me, it is necessary to follow any indications provided by the care team, such as:

- KEEPING BODY WEIGHT MONITORED
- EXERCISING REGULARLY
- FOLLOWING AN ADEQUATE DIET AND RESPECTING THE PRESCRIBED DRUG THERAPY
- ALWAYS BRING LISTS OR DIGITAL MEASUREMENTS OF YOUR BLOOD GLUCOSE LEVELS WITH YOU AT YOUR CHECK-UPS.

Also in this case it is important to be able to detect early symptoms and report to the doctor any recent symptoms such as:

INCREASED THIRST	INCREASE IN THE AMOUNT OF URINE PASSED	DISTURBED VISION	MENTAL CONFUSION	FATIGUE
---------------------	--	---------------------	---------------------	---------

Hypertension

After the transplant, I have to take blood pressure frequently and take medications, if needed, to control it.

Following the indications received from the clinical center, I might have to measure and note blood pressure values and to take antihypertensive therapy as prescribed.

(E.G. BLOOD PRESSURE TABLETS OR MEDICATION)

General tips to try to follow:

AVOID STRESS AND REST WHEN NEEDED

REDUCE SALT IN THE DIET

DO NOT SMOKE

EXERCISE REGULARLY

FOLLOW THE DIET THAT HAS BEEN PRESCRIBED AND TRY NOT TO GAIN WEIGHT

Neurological complications

My doctor explained to me that some immunosuppressive drugs can trigger neurological reactions.

These symptoms are mostly experienced in the first period after the transplantation, and generally fade when the immunosuppressive drugs are reduced.

Some of them might be:

SLEEP DISORDERS, SUCH AS INSOMNIA, HALLUCINATIONS, NIGHTMARES

IRRITABILITY AND MOOD CHANGES

TREMORS

TINGLING HANDS AND FEET

DIFFICULTY CONCENTRATING AND MEMORY IMPAIRMENT

I need to remember that it is important to discuss with my medical team about any experienced side effect and any variation that I notice:

AS SAID, I CAN AND I NEED TO TALK ABOUT EVERYTHING WITH MY DOCTOR, ALONG ALL THE WAY!

Cancers

My doctor recommended also to reduce any risk factors, such as to avoid cigarette smoking and protect the skin during sun exposure.

(WELL, ISN'T THAT TRUE FOR EVERYONE?!)

Some advice?

- WEARING SUITABLE SUNSCREENS,
- AVOIDING EXPOSURE TO THE SUN IN THE CENTRAL HOURS OF THE DAY,
- WEARING HATS AND CLOTHING THAT LIMIT THE AREAS OF THE BODY DIRECTLY EXPOSED TO THE SUN, ESPECIALLY IN THE SUMMER.



It is also important to report to the doctor the possible appearance of:

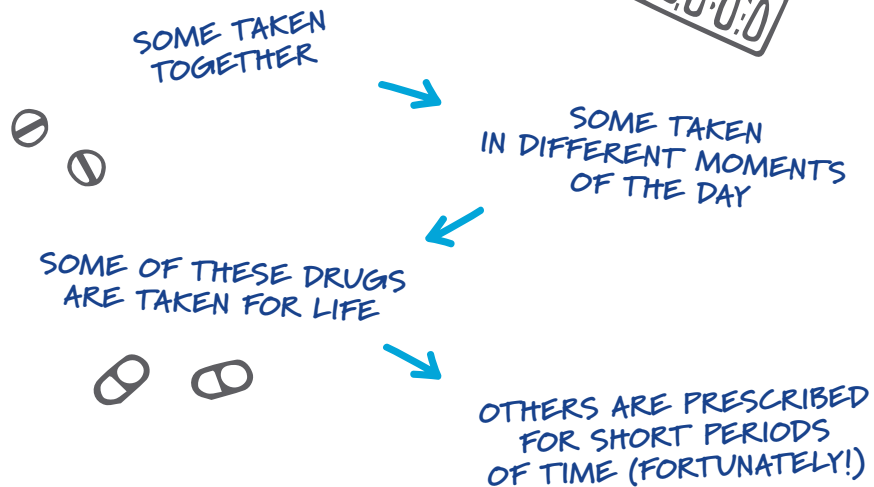
SKIN SPOTS

ALTERATION OF THE NEVI

UNUSUAL LYMPH NODE SWELLING

Management of immunosuppressive drugs

The purpose of immunosuppressive treatment is to prevent of rejection.
Therapy generally consists of different drugs,



It is important to follow the treatment for the necessary duration indicated by the doctor to help my new kidney to stay in good health for as long as possible and further improve one's quality of life.

IT IS IMPORTANT TO LEARN HOW TO ADOPT PRACTICAL MEASURES THAT ALLOW TO MAXIMIZE THE PROTECTIVE EFFECT OF THE THERAPY AND REDUCE ANY RISKS.

Here some examples:

TAKE DRUGS AT THE SAME TIME EVERY DAY, AS PRESCRIBED

DO NOT CHANGE OR SKIP THE DRUG DOSE

ASK YOUR DOCTOR WHAT IS THE CORRECT WAY TO BEHAVE IN CASE ONE FORGETS TO TAKE A DOSE

CONTACT THE DOCTOR IF A HIGHER DOSE THAN PRESCRIBED IS ACCIDENTALLY TAKEN

ALWAYS CHECK THE EXPIRATION DATE OF THE DRUGS SHOWN ON THE LABEL

STORE THE MEDICINES IN A COOL, DRY PLACE, AWAY FROM LIGHT AND OUT OF REACH OF CHILDREN

DO NOT PLACE MEDICINES IN THE REFRIGERATOR UNLESS SPECIFICALLY INSTRUCTED BY THE DOCTOR OR PHARMACIST

ALWAYS CHECK THERE IS A SUFFICIENT SUPPLY OF MEDICATION, ESPECIALLY CLOSE TO THE WEEKEND OR IF ONE IS ABOUT TO LEAVE FOR VACATION

TELL THE DOCTOR RIGHT AWAY IF ANY NEW OR UNUSUAL SIDE EFFECTS EXPERIENCE OCCUR

CHECK IF THE MEDICATIONS TAKEN INTERACT WITH CERTAIN TYPES OF FOOD AND DRINK

(LUCKILY I NEVER LIKED GRAPEFRUIT AS THIS IS ONE OF THE FOODS THAT HAS A NEGATIVE EFFECT ON THE MEDS IF TAKEN!)

It is also important to pay the utmost attention every time when taking new medicines, even over the counter, and to contact the doctor of the Transplant Center:

even in the case of homeopathic or herbal products, these should not be taken without first consulting the doctor.

CONTACT INFO

And what about COVID-19?



People taking immunosuppressive drugs need to be very careful with respiratory virus infections, including COVID-19.

For this specific reason it is important to adopt the following preventive measures:

DO NOT SUSPEND
THE IMMUNOSUPPRESSIVE THERAPY
IN PROGRESS, UNLESS OTHERWISE
INDICATED BY THE DOCTOR

WEAR A MASK

AVOID CROWDED PLACES
AND CLOSED ENVIRONMENTS

KEEP A DISTANCE OF AT LEAST
ONE METER FROM OTHER PEOPLE

AVOID TOUCHING FACE, EYES,
NOSE AND MOUTH WITH HANDS

AVOID HUGS AND HANDSHAKES

^
**THIS IS ONE OF THE MOST
DIFFICULT TASK**

SNEEZE OR COUGH
INTO A HANDKERCHIEF

AVOID HOME VISITS BY PEOPLE WITH SYMPTOMS
AND/OR FROM AREAS AT RISK

CLEAN THE SURFACES AND THEN DISINFECT THEM
WITH DILUTED BLEACH OR
ALCOHOL

If I have doubts or symptoms, staying home and calling my doctor is always the easiest solution!

Hey, there's a lot of stuff to deal with, right?

**SOMETIMES I ASK MYSELF
HOW CAN I GO THROUGH ALL OF THIS.**

BUT THEN I REMEMBER I'M NOT ALONE.

I remind myself how much more free my life is now that I am not bound to dialysis, and how much better I feel now when all the symptoms caused by my kidney failure are gone.

I have people that care about me and are willing to help, my care team is always by my side and I feel that I always have the support that I need in my everyday life.

See you soon,
Elle

Suggested readings

SPECIALIZED ARTICLES:

- **Position statement on measures to reduce the risk of COVID-19 in solid organ transplants recipients by use of vaccinations, immune testing, and public health policies.**

Download available at: https://esot.org/wp-content/uploads/2022/02/Position-statement_COVID19-Vaccination_15.02.2022_FINAL.pdf

Date accessed: 28 April 2023.

IN-DEPTH ARTICLES:

- **Che cos'è il trapianto di rene.**

Download available at: <https://www.maggioreosp.novara.it/che-cose-il-trapianto-di-rene/>.

Date accessed: 13 March 2023.

- **Come proteggersi dal Covid-19. Ministero della Salute.**

Available at: <http://www.salute.gov.it/portale/nuovocoronavirus/dettaglioFaqNuovoCoronavirus.jsp?lingua=italiano&id=235#6>.

Date accessed: 13 March 2023.

- **Covid-19, raccomandazioni per le persone immunodepresse. Ministero della Salute.**

Download available at: <http://www.trovanorme.salute.gov.it/norme/renderNormsanPdf?anno=2020&codLeg=73753&parte=1%20&serie=null>

Date accessed: 13 March 2023.

- **La vita continua! Guida informativa per i pazienti in attesa di e con trapianto renale.**

Download available at: https://www.asst-settelaghi.it/documents/41522/2486281/0654_15X-OPUSCOLO10x21.pdf/45ad9e93-35bb-0cd3-3784-ad670a518707.

Date accessed: 13 March 2023.

- **Q&A: Small public gatherings and COVID-19. World Health Organization.**

Available at: <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/question-and-answers-hub/q-a-detail/q-a-small-public-gatherings-and-covid-19>.

Date accessed: 13 March 2023.

- **Un bene prezioso da tutelare.**

Download available at: <https://www.aovr.veneto.it/documents/20182/31037/un-bene-prezioso-da-tutelare.pdf/8e23c662-f454-4ea1-856c-a71bb5cb3c7b>.

Date accessed: 13 March 2023.

"EVERY SUNRISE
BEGINS
WITH NEW EYES."

-CIT.-

Chapter 5

my new **LIFESTYLE**

New habits I've learned
for my healthy new life.


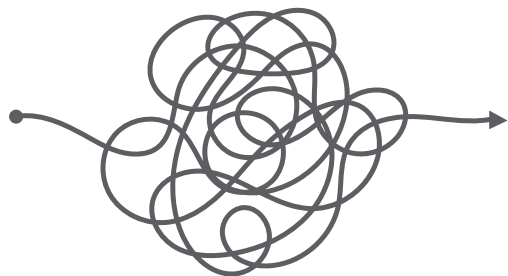
Dear Diary,
It seems like a lifetime ago
that I was going through
my dialysis sessions.

In some ways it feels like it was an easier life:
I knew the procedure, I knew how I was about to feel,
what to expect from my body and how to deal with the pain.

I mean, I had to get used to it, so I did.

Since the transplant, this new life is another story.
Everything has changed, for the better
OBVIOUSLY

thanks to the personalized approach my care team has been giving me.
However it's not all been plain sailing, and there have also been some
challenging moments.



Everything is new, every day I learn something about
myself, and every day I try to build habits
in order to make this brand new life a better,
healthier and happier life.

I have to tell you, at the beginning, adapting my lifestyle to keep my
new kidney healthy and functioning seemed like an impossible task,
or an imposed duty I had to fulfill.

**BUT THEN I STARTED TO REALIZE
I AM THE ONLY ONE WHO CAN
REALLY LEAD THIS CHANGE,**

and now that a new path is ahead of me, the
only way I can truly feel myself is to walk it.

NOTE TO SELF:

"THE SECRET OF CHANGE IS
TO FOCUS ALL YOUR ENERGY,
NOT ON FIGHTING THE OLD,
BUT ON BUILDING THE
NEW."
SOCRATES

**A QUOTE THAT
INSPIRES ME**

I BELIEVE I AM BUILDING THE NEW ME RIGHT NOW, EVERY MOMENT.

It's not easy, but I've found out that talking to Dr. Nichols and my care team about anything that worries me or issues me is the foundation of a good, healthy (physically and mentally) and safe post-transplant journey.

That's why I think it's so important to write about the changes I'm making,

THE BIG ONES AND THE LITTLE ONES



TEL NUMBERS:

to sum them up and figure out the progress that I'm making.

I ALSO TAKE THE TELEPHONE NUMBERS OF MY CLINICAL CENTER WITH ME, ALWAYS READY FOR EVERY EVENTUALITY.

General precautions

When starting a new journey, organization is key! I've found it very important to always keep at hand a detailed list of the therapies to be taken.

Monday Tuesday Wednesday Thursday Friday Saturday Sunday

6 am

7

8

9

10

11

12

1 pm

2

3

4

5

6

7

8

This will help me, managing my time, my visits and medications, but it's also necessary to make the healthcare staff aware of my condition during follow-ups or in case of accidents.

I JUST LOVE SMILING,
AND I WANT TO KEEP MY TEETH HEALTHY
FOR AS LONG AS POSSIBLE!

While it might be better to wait at least three months post-transplant
before scheduling routine dental work,



a healthy mouth remains an important part
of staying "infection free" after transplant.

Because immunosuppressive medications
can have side effects that can cause dental problems
and can also make your mouth more susceptible to:



- to dry mouth,
- bacterial
- or other types of infections

* I NEED TO REMEMBER

TO PLAN VISITS TO THE DENTIST
ON A REGULAR BASIS
TO AVOID INFECTIONS IN THE MOUTH.



"KEEP SMILING, BECAUSE
LIFE IS A BEAUTIFUL
THING AND THERE'S SO
MUCH TO SMILE ABOUT"

M. MONROE

Alcohol and smoking

Good habits should always be embraced, no matter who we are,
how we feel, and what we are facing.

But of course it's vital for me, as a post-transplant person,
to avoid the abuse of alcoholic beverages.

There's always something more tasty and healthy
to have a toast with!

You know I've never smoked,
but now more than ever it's important to avoid it,
since it causes serious damage the cardiovascular system,
the onset of some neoplasms and it can worsen respiratory tract diseases.

Water to drink

WELL, NOT FOR EVERYONE!
↓

What's easier than drinking a glass of water?

I've always been careful with the type of water I put into my body, but now it's more important than ever paying attention to what I drink.

My physician told me I can drink tap water, but he also told me that if **I'm not sure about the quality** and the safety of the source, it's better for me to lean towards packaged water. I can buy whatever brand of water I prefer, there's no big difference, **but he suggested to me that it's better to avoid well or spring water.**

I also keep track of how much water I drink, in order to introduce the daily amount Dr. Nichols recommended it to me.

DRINK PLENTY!

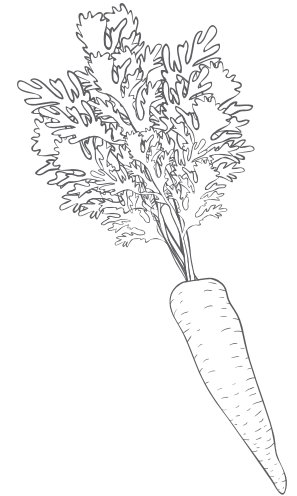
M	☹️ ☹️ ☹️
T	☹️ ☹️ ☹️
W	☹️ ☹️ ☹️
T	☹️ ☹️ ☹️
F	☹️ ☹️ ☹️
S	☹️ ☹️ ☹️
S	☹️ ☹️ ☹️

Diet

My post-transplant diet was the biggest revolution of all! You wouldn't tell, but my diet indications are now more loose than what before the surgery.

I have only few restrictions:

- I can eat bread, pasta and rice but only in adequate amount and preferably wholemeal
- I need to wash very thoughtfully fruits and veggies
- I need to avoid excessive salt in my diet
- I have to pay attention not to exceed calories, sugars and fats.



Risk of infections

one of my biggest fears so far is to contract an infection.

The care team who followed me along this journey have been so supportive and helpful, providing me all the information I needed to live a normal, while still careful, life.

First of all I've discovered I don't need to be isolated from the world, or to limit contact with others. I just need to adopt some precautions.

1.

I have to make sure **to avoid contact with people who have an ongoing infectious disease**, especially if it is a viral disease like chicken pox, mumps, measles, mononucleosis, tuberculosis or the more common flu.

And of course in this particular historical moment I must avoid crowded places and use masks to prevent myself from getting COVID-19.

2.

I take any drugs prescribed for prevention of infection and I'll take antibiotics whenever I would need to go under dental treatment

or other medical procedures like gastroscopy, colonoscopy, removal of skin nevi or polyps etc.

I always wash my hands, especially before meals or before handling food, and I always have hand sanitizer ready to use when I touch objects like money, door handlers, public transport vehicles or after using the toilet, especially if in public.

3.

When my hands are not clean, I pay attention not to touch my eyes, mouth or nose.

BUT THIS IS SOMETHING EVERYONE HAS TO LEARN NOT TO DO NOWADAYS, ISN'T IT?

4.

I avoid places where a lot of dust and dander is in the air, like construction sites, barns, shelters for animals or fertilized land.

5.

I make sure to be wearing gloves in my outdoor activities, especially gardening, during which I can get infections from accidental cuts.

For the same reason, I don't go outdoors barefoot.

6.

My shoes collection is too nice to not always wear a pair of them!



7. I have my own razors, toothbrushes and dishes, and I don't share them with anyone,

7.

even if they are family members.

Exposure to toxic chemicals

IN THIS NEW LIFE I'VE FOUND OUT I MUST PAY ATTENTION TO THE ENVIRONMENT AROUND ME.

In Fact what was once totally normal to use, now can be dangerous to me. As a transplant person, I tend to avoid the use of those products or not to inhale their potentially harmful fumes:



- dyes
- solvents
- pesticides
- insecticides
- petrol



Whenever I really need to use them, I put on some gloves, protective goggles, a face mask (nowadays we all have one of it at hand) and I always open the windows, no matter the weather, to ventilate the environment.

Exercise

Being a post-transplant patient is no excuse for not staying active.

Apparently after evaluating my physical condition and age, Dr. Nichols has confirmed that for me it's good to practice physical activity.



In fact I can get many benefits from exercising:

- it strengthen my muscles
- it keeps the joints active
- it keep my body weight under control
- it improves cardiovascular function
- and of course it reduces stress

I'M A HUGE FAN OF SPORTS

LIKE SWIMMING, RUNNING, CYCLING, AND I ALSO LOVE TAKING GOOD WALKS.

EVEN A SIMPLE 30 MINUTES WALKING CAN BE GREAT FOR YOUR BODY AND YOUR MIND, ESPECIALLY WALKING IN THE NATURE, SEASIDE OR FOREST!

However, I must discuss with the physician and my care team before starting any new activity, and we must evaluate case-by-case.

Generally, I've been told it's better to avoid heavy lifting or any contact sports like football, boxing, martial arts, motorcycling, in which I can have some trauma that can damage the transplanted kidney.

NOTE TO SELF:

WHEN DOING SPORTING ACTIVITIES THAT INVOLVE A LOSS OF WATER AND SALT, I NEED TO MAKE SURE TO STAY CAREFULLY HYDRATED.

Owning a pet

For nothing in the world I could have separated from Marley, my little paw friend!

As a post-transplant person, owning a pet is not a problem, but it takes some extra effort.

- I need to keep my pet on regular veterinary checkups and vaccines.
- I make someone else do all the bad stuff like cleaning cages, kennels and litter boxes. When I don't have a choice and I have to do it myself, I make sure to wear gloves and to wash my hands thoroughly after finishing.
- I avoid contact with its urine, faeces and vomit.
- I always wash my hand after petting it. **BUT THAT'S ALWAYS BEEN EWWW!**

Travel

The kidney transplant has opened me a new life, by opening me new possibilities that I couldn't even imagine before.

LIKE TRAVELLING!

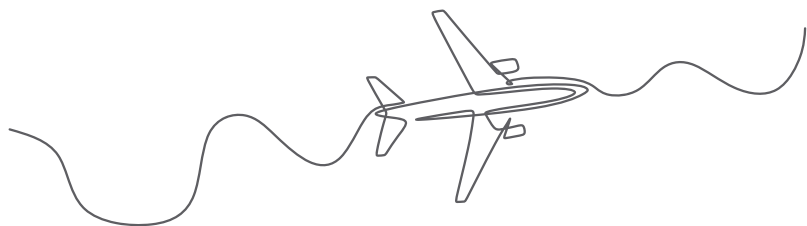
Although COVID-19 is still there and we still need to be careful, things are getting better and we can finally travel again! However, it's better to play it safe and check which precautions can help...

In this first period, just after the transplant, the care team recommended that I only visit developed countries and to avoid regions of the world where sufficient hygiene is not guaranteed.

Anyway, before planning a trip, I will discuss it with my care team about the duration and the destination.

They will let me know all about the precautions I will need to take, such as preventive vaccinations, antibiotics as prophylaxis or treatment for travel diarrhea.

For example, I cannot receive "live" vaccines such as the yellow fever, and the discussion with the care team can really help there!



If the chosen destination has a very different time zone from mine, I'm sure they will also help me with adapting my medicines intake time.

NOTE TO THE FUTURE TRAVELLER IN ME:

- Make sure to take the necessary amount of medications to cover the entire time of the holiday with you plus a few extra days in case of any delays (ie. flight cancellations)
- Better packing the drugs in two different places, so as not to lose the entire supply if a baggage is lost.
- Remember to put medicines in hand luggage rather than checked in the hold!

During my future travels, I will need to pay extra-attention to what I'm going to eat.

A big "no no" will be raw fish, meat, eggs and vegetables, if I am not sure of the origin and genuineness of the products. It will also be safer for me and for oral hygiene to drink only bottled water, and to avoid public toilets.

A DIET CAN PLAY AN IMPORTANT ROLE IN HELPING YOUR KIDNEY, ESPECIALLY WHEN TRAVELLING...

- Do not eat street food, especially raw foods such as sushi etc.
- Some foods should not be eaten, as high altitudes may change how our taste buds appreciate certain tastes (or not!) ... pasta not recommended!
- Always best to pack healthy snacks with me.
- Drink clean water.



In case of diarrhea,
I should be calling my physician right
away, use any prescribed therapy
and discuss a quick detox diet
like a slag-free

So, my dear diary,
It's been a long journey, hasn't it?

Looking backward, I find it so rewarding and uplifting to have been able to make it
through my kidney transplant path.

But I have to admit that I would never be able to face every challenge, every bad
moment, every fear and doubt without my supportive and qualified medical team.

AND ALSO WITHOUT YOU

Talking to you about my journey, expressing my feelings, and letting others know
what to expect is the best part of it, and what certainly made it possible for me
to start writing my next chapter.

love,
Elle

Suggested readings

SPECIALIZED ARTICLES:

- Weinberg MA et al., Medical and dental standardization for solid organ transplant recipients, N Y State Dent J. 2013 Nov;79(6):35-40.

IN-DEPTH ARTICLES:

- Holiday / travel vaccinations in transplant patients - National Kidney Federation.
Available at: <https://www.kidney.org.uk/holiday-travel-vaccinations-in-transplant-patients>.
Date accessed: 13 March 2023.
- Che cos'è il trapianto di rene.
Download available at: <https://www.maggioreosp.novara.it/che-cose-il-trapianto-di-rene/>.
Date accessed: 13 March 2023.
- Un bene prezioso da tutelare.
Download available at: <https://www.aovr.veneto.it/documents/20182/31037/un-bene-prezioso-da-tutelare.pdf/8e23c662-f454-4ea1-856c-a71bb5cb3c7b>.
Date accessed: 13 March 2023.
- La vita continua! Guida informativa per i pazienti in attesa di e con trapianto renale.
Download available at: https://www.asst-settelaghi.it/documents/41522/2486281/0654_15X-OPUSCOLO10x21.pdf/45ad9e93-35bb-0cd3-3784-ad670a518707.
Date accessed: 13 March 2023.

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We would like to extend our thanks and to acknowledge the contribution of all the people who have received a transplant and all the representatives of the allied HCPs that have helped with the creation of the contents of this Diary.