THINGS WE WISHED OURSELVES KNEW SOONER

1. You have you to educate yourself and everyone else

It is beyond sad and annoying that thalassaemia is still not well known or spoken about so it's on you read to read as much as you can from a reliable source and preach to the masses! You got this!
It’s hard to be a good friend when you cancel plans last minute. It’s hard to be a good partner or parent when you barely have the energy to get out of bed. No matter how much you try to explain, people expect you to get better already — and when you don’t, they resent you, consciously or not. Some relationships end entirely, casualties of an unfair and misunderstood illness, while others get stronger as you find your true support system.

Everyone will give you advice

People are compelled to offer advice about thalassaemia because they’re convinced a simple fix or cure must exist {insert new diet, more prayers, wheat grass, blah blah} - if you’re on the receiving end of this advice, say something like, “I appreciate that you’re trying to help, but my doctors and I think this treatment is best right now” or "Thank you, but that wouldn’t help. Here’s how my condition works, and here’s the kind of treatment that’s required."
Support is everything!!
Loved ones try their best but fellow patients are the ones that really understand what you may be feeling reach out to them- experiencing this alone can be isolating.

The mental aspect can be as hard as the physical
There is trauma, there is self depreciation, there is a daily internal fight to keep up with your treatment- but despite the down times, you are resilient and stronger than anyone else you know. If you are struggling ask for help!

Taking your iron chelation as prescribed
We know it is difficult and not to mention an annoying daily reminder, but the earlier you get into a routine, the easier it becomes. Not to mention, you may be able to skip some of the trauma and secondary conditions that come with poor adherence. INVEST IN YOUR FUTURE