Missing something:

If you're like others living with sickle cell disease (SCD) or caring for someone who does, you might have missed an appointment in the last year.*

Everyone misses appointments sometimes - people who work in SCD clinics share they've missed an appointment in the past year, too.

This graphic suggests some steps to find solutions and help make getting to appointments easier.

*Most adults and children living with sickle cell disease missed at least one clinic appointment in a year, according to a study by an Atlanta regional SCD center.



Step 1. Get ready by knowing your challenges.







So many doctor visits, work priorities, school conflicts, and other people to take care of.





CONFUSION

Whether appointments are in different offices or you don't get clinic reminders, the problem is the same: where to be and when to be there.





Cars, buses, subways, Ubers, Lyfts, friends...no matter how you get there, it seems something can always go wrong.





It can equal a missed visit if you aren't prepared for a procedure or if there's an insurance issue.





Everyone's different, and there are lots of ways getting to appointments can be hard. Think honestly about your own challenges and put them here.



Step 2. Get set with some resources.

Community-based SCD organizations are here to support you! They provide info and lots of services - education, information, support groups, insurance help, and more for families and adults living with SCD.

Find a local SCD organization online. If there are none close by, call the nearest organization and ask about online services or other options.

Step 3. Go with a conversation.

Your doctor or clinic staff can be a major part of the appointment solution. Here are some ways you can start the conversation...



"I have a lot of problems with getting here to the clinic. Who should I talk to about getting some help?"



"I don't seem to get the clinic calendar alerts regularly. Can we go over the system?"



"Our appointment got canceled because when we came, we weren't ready for the blood test. How do I get the information in advance?"



"I see multiple doctors in this building. Can we coordinate so those appointments are on the same day?"



"I have lots of things going on in my life. I need an advocate, someone I can talk to and who understands. Can you help me with that?"

You can also find information and tools on NICHQ.org that you can share with your clinic.

And share this QR code with your provider and clinic staff so they can find information and resources, too.

