

Independent Living Skills for Individuals with X and Y chromosome variations

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Disclosures: None

Independent Living

Is my child ready?



Independent Living Skills

- Staying Healthy
- Day – to - Day Living things
- Keeping it Safe
- Social Skills
- Social Connections
- Day- to - Day Financial management

How to Support Decision Making and Learning: Path to Independence



Realistic Goals
Child's Interests and Abilities
Environment and Resources

Staying Healthy: Medications

Things to know about meds:

- Why you need to take them?
- What happens if you missed doses?
- Adverse effects
- Who prescribes them?

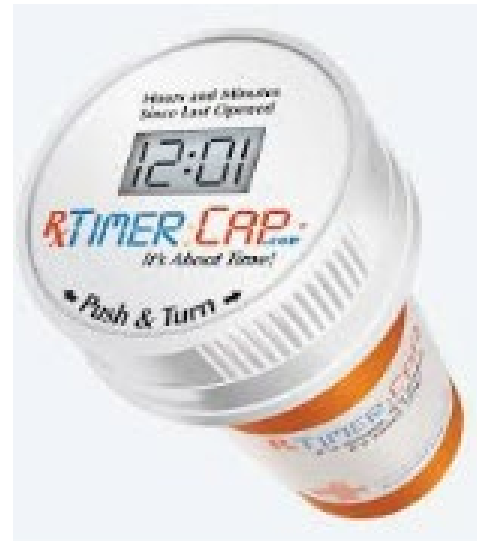
Staying Healthy: Medications

How to take them independently



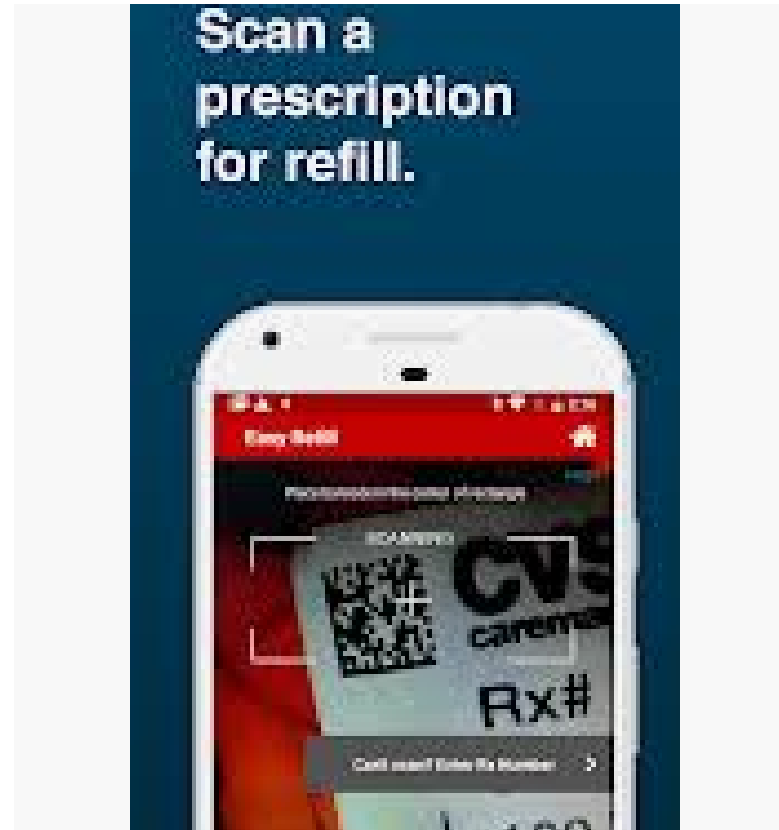
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Staying Healthy: Medications

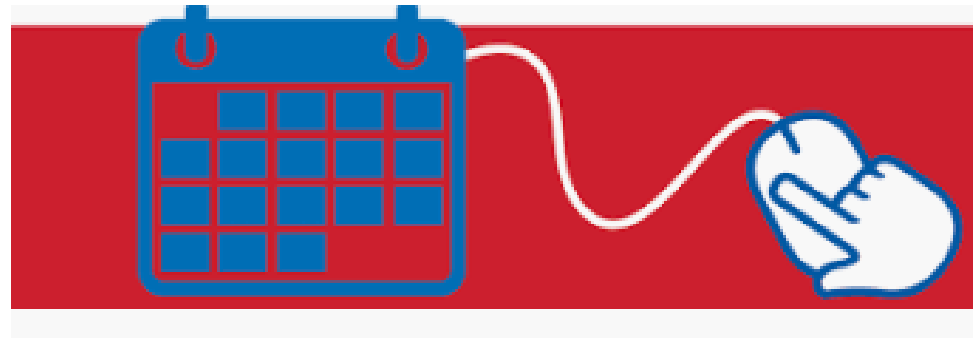
How to manage refills



CVS Caremark - Apps on Go...

Staying Healthy

Keeping up with doctor's appointments



Day- to - Day Living things

Cooking

Personal Hygiene & Laundry

Driving & Transportation

Keeping it Safe

Food safety

Personal safety

cell phone GPS locator, landlines, when to call 911

Internet Safety

Netnanny

How to interact with police

Social Skills

Finding and keeping a job

- Identifying personal interests & abilities
- Interviewing
- Asking for accommodations
- Keeping a schedule
- Staying on task



Social Connections

Bulling & Self-Advocacy

Disclosure

Sexuality & dating

Disclosure- Telling Others

- School/ Work
 - Advocacy for Resources & Accommodation
 - Misconception as lazy
- Family & Friends
 - Right to privacy
 - Misinformation by internet & social media
- Dates

Disclosure

What we know from research on other genetic conditions

Challenges: Whether, when, what and how to tell

Concerns: fear of rejection

- too soon or too late

- how much detail to disclose

What may influence decision to disclose:

- individual and family attitudes and beliefs

- getting to know other families may help

Strategies: open vs. selective

Disclosure-How to tell

- In person- no text or emails
- Make a plan according to circumstances
- Be truthful & keep a positive attitude
- Framed in the context of the individual (not what is written in textbooks or internet)
- Use simple terms and direct language



Thank you!



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Klinefelter and other XY Variations Program