



Living with Type 1 Diabetes: The Role of Information in Care & Self-Management

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Understanding how the need for specific information evolves with life events and care transitions.

STAGES

01 DIAGNOSIS

Usually triggered by life-threatening episode. Care focus is immediate stabilization, blood tests, confirming T1D. Involved stakeholders emergency staff, internist, and overwhelmed family members.

PATIENT EXPERIENCE

"I was scared, the setting was intense. And results could have been fatal"



KNOWLEDGE TRANSFER

Reactive Approach

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GAPS

- Fear-based communication without emotional support
- Information overload with little time to process
- Generic, non-personalized education
- Crisis/ICU-based care entry without smooth follow-up or transition

02 ONBOARDING

Initial phase of education during the "honeymoon period," when residual insulin production creates a false sense of ease. Focus is on delivering intensive, multidisciplinary information on treatment, diet, devices, and emotional support.



"I am not able to ask questions about my sex life in front of my parents to my internist"

03 ADJUSTMENT

Adjusting treatment plans with regards to insulin management as well as diet. Care focus is Tailoring care to lifestyle and refining insulin routines and device usage.



"Docs call this honeymoon period.....but I think T1D is easy right now"

04 TRANSITION

Shifting responsibility from parent-supported pediatric care to independent self-management in adult care. Only Applicable to minors diagnosed with T1D.



"My parents & doctors want me to think about long term effects when managing T1D but for me right now it is more about just getting through"

05 INTEGRATED CARE MANAGEMENT

Long-term self-management with periodic professional check-ins, increasingly shaped by life context. This phase can be seen in 3 phases as follows,

MONITOR & RESPOND

Patients handle day-to-day issues between visits.

"The association really helped me and I feel supported, I always reach out to them to know more form their experience"

MANAGE TREATMENT & LIFESTYLE

Re-engagement with providers and insurers due to life changes or new treatments.



"I just see my doctor thrice a year and I am not able to discuss much as most time is spent discussing the report and time in range..."

LEARN, PLAN & CONNECT

Proactive learning from peer stories and content found.

"Consultations with my doctors have same pattern as long as I stay in the range....I am good"