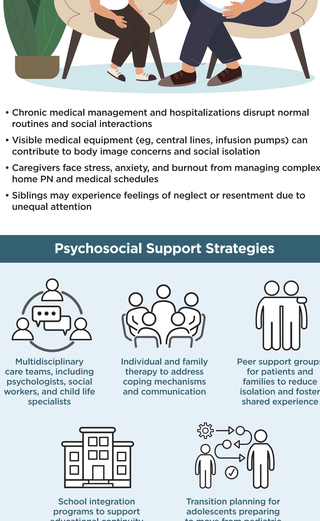
Addressing Psychosocial Needs of Children and Adolescents Living With SBS and Their Families



Pediatric and adolescent patients living with SBS face unique psychosocial challenges due to chronic illness management, reliance on PN, and frequent medical interventions. These challenges extend beyond the patient — affecting family dynamics, caregiver well-being, and social development. A proactive, multidisciplinary approach that integrates psychosocial support can help optimize QOL, promote treatment adherence, and foster resilience for both patients and their families.

Understanding the Psychosocial Burden



- Chronic medical management and hospitalizations disrupt normal routines and social interactions
- Visible medical equipment (eg, central lines, infusion pumps) can contribute to body image concerns and social isolation
- Caregivers face stress, anxiety, and burnout from managing complex home PN and medical schedules
- Siblings may experience feelings of neglect or resentment due to unequal attention

Psychosocial Support Strategies

Multidisciplinary care teams, including psychologists, social workers, and child life specialists

Individual and family therapy to address coping mechanisms and communication

Peer support groups for patients and families to reduce isolation and foster shared experience

School integration programs to support educational continuity and peer acceptance

Transition planning for adolescents preparing to move from pediatric to adult care

Transition Planning for Ages 13 to 21+

TRA

Early (13-14)
Middle (15-16)
Late (17+)
Parent Form

Action Plan

- Transition clinic
- Learning modules
- Skill building
- Peer support (camp, ENCORE, Parent Form)
- CHP Bridges conference

Assessment → **Interventions** → **Reassess**

Transfer Prep

- Final TRA
- Early engagement of adult team

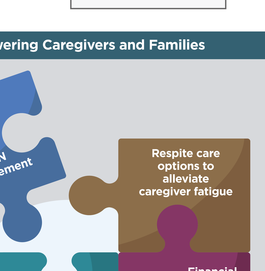
- Annual clinic with multi-disciplinary team
  - — Review checklists
  - — Progress through early, middle, and late TRA skills
  - — Update TRA

Empowering Caregivers and Families



Supporting Psychosocial Development in Adolescents

- Encouraging independence and self-management skills as appropriate
- Addressing body image and identity concerns linked to visible medical devices
- Facilitating social participation through adaptive activities and virtual communities
- Guiding transition to adult care with mentorship and structured planning



Key Takeaways

Psychosocial health is central to holistic SBS management and long-term outcomes

Emotional support should be integrated early and continuously across the care journey

Collaboration among medical, psychological, and social care teams enhances coping and QOL

Empowering families with education, peer connection, and resources reduces caregiver burden

Adolescents benefit from structured support to foster independence and transition readiness

Abbreviations

PN: parenteral nutrition
QOL: quality of life
SBS: short bowel syndrome
TRA: transition readiness assessment

References

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