

Fanconi Anaemia Stages of Life: From Diagnosis to Adulthood

Emotional Adjustment

Family Adaptation

School Support

Coping Strategies

Identity Development

Independence

Life Planning

Psychosocial Aspects

Diagnosis

- Physical signs or blood count changes
- Chromosome breakage test
- Genetic testing
- Family support and education
- Establishing baseline health

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Medical Management

- Regular blood count monitoring
- Managing symptoms
- Androgens or growth factors
- Transfusion support
- Building medical team

3>

Transplant Decision

- Evaluating timing for transplant
- Donor search and selection
- Family planning discussions
- Pre-transplant evaluations
- Emotional preparation

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Transplant & Recovery

- Conditioning regimen
- Stem cell infusion
- Hospital isolation period
- Engraftment monitoring
- Managing complications

5>

Post-Transplant Life

- Follow-up care
- Managing late effects
- Return to school/activities
- Psychological adjustment
- Family adaptation

6>

Adolescence & Transition

- Identity
 development
- Transition to adult care
- Educational/
 vocational planning
- Social relationships
- Independence skills

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Adulthood with FA

- Long-term heath monitoring
- Cancer prevention strategies
- Reproductive considerations
- Career and life planning
- Maintaining quality of life

Diagnosis & Baseline

Monitoring & Support

Transplant Planning

Treatment & Recovery

Follow-up
Care

Adult Healthcare

Long-term Surveillance

Medical Aspects



Throughout the journey:

- Focus on hope and resilience
- Celebrate milestones
- Build support networks
- Stay informed about research advances



Family Impact:

- Parents & caregivers
- Siblings

- Extended family
- Support networks
- Set-care strategies



Please note: This diagram is indicative only, as both the psychosocial and medical experiences of FA vary widely between individuals. Please also note that current FA-specific psychosocial research is limited so this diagram is largely based on lived experience.