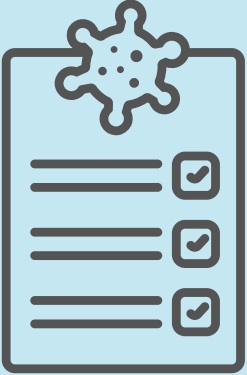


# STAGES OF LIFE WITH FANCONI ANEMIA

This visual offers a potential progression of living with FA. Remember that every individual may progress uniquely along the FA journey.



## STAGE 1: DIAGNOSIS

AGE 1-5

Typically, children are diagnosed before age five, though not always. Diagnosis often entails feeling shocked, devastated, terrified, and unsure of how to proceed. Families are taking in a lot of new and potentially confusing information and trying to determine the best next steps for the future. It's also a time where families may feel isolated within their own communities, but are beginning to form valuable connections within the FA community.

SOURCE: STELLA DAVIES, MBBS, PHD, MRCP  
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CENTER JUNE 2020 | FA FAMILY MEETING

The elementary school years are often spent waiting and wondering if/when a bone marrow transplant (BMT) will happen. Not everyone will need a transplant, so the waiting and wondering can sometimes feel more stressful than actually going through the transplant process. The BMT procedure involves a couple days of pre-conditioning, then after the transfer of cells and recovery, patients are usually requested to stay near the hospital for about 100 days.

## STAGE 2: WAITING

AGE 5-12



## STAGE 3: WATCHING

AGE 12-18

As children enter adolescence, families begin to shift focus to watching for the development of head and neck or gynecologic cancer. All individuals with FA should begin cancer screening visits with doctors at a young age regardless of whether they have gone through a bone marrow transplant.

## STAGE 4: GROWING

AGE 19+

Entering adulthood comes with its own set of milestones, which may include moving out of the home, becoming independent, getting a job, or forming relationships. These transitions are accompanied by additional challenges, such as securing a physician who specializes in long-term care for adults with FA, and transitioning from guardian health insurance plans to new personal coverage. Regular screening for cancer is imperative in adulthood, as it becomes more prevalent with age.

