

Online Resource 1 Language used by patients with Alagille syndrome to describe itching

Age, years	Description	Severity	When	Frequency	Duration	Location
3–5	Feeling itchy	No information reported	When lying in bed, when a mosquito bites	No information reported	No information reported	Legs, back, body, arm, feet
6–8	Scratching, like a mosquito, struck by lightning	No information reported	In the middle of the day, when outside, when waking up, when playing sports, during the middle of the night	Every day, every 3 hours, 3–4 times daily, twice daily	No information reported	Head, forehead, legs, middle of skin, arm, elbow joint, shoulder blade, back, stomach, all over body
9–11	Tingling, mosquito bite, urge to scratch, like an allergy	Never stopping, breaking skin open, itching fits	During the summer, at night	Once a day, every day	2 minutes	Ankles, legs, back, arms, hands, feet, head

Age, years	Description	Severity	When	Frequency	Duration	Location
12– 17	Irritated	Really bad, too itchy, breaking skin, itch so bad that your skin comes off	When getting home from school, when laying down	Five times per day	A minute, 5 minutes, an hour or two, until patient lays down and gets back up	Feet, nose, neck, back, knees, legs, arms
≥18	Itching, scratching	Not as bad as some people	When lying in bed, when watching television, at night	Fifteen times per day	A couple of minutes, 10 minutes, 3 hours	Back of head, all over, legs

Only patients aged 9 years and older were able to describe the severity or duration of their itching