Endocrinologists Share Patient Stores on Access to Affordable Insulin

These stories are a sample of the stories endocrinologists around the country have shared with the Endocrine Society concerning their patients’ lack of access to affordable insulin. The stories have been slightly edited for length and clarity. If you have questions or would like to discuss further, please contact advocacy@endocrine.org.

Please see our position statement for more information about the Endocrine Society’s position on insulin affordability.

“The prices are obnoxiously high! Even patients with good insurance are constantly worried about not having been given enough insulin by insurance providers. Insurance providers, facing high insulin costs, are constantly trying to find strategies to limit insulin supplies for patients. Further, they keep changing their preferred insulin on their formularies based on the lowest negotiated cost of insulin, but at the cost of the poor patient—who does not understand why their medication is being changed without their consent.”

- Indrajit M.
  New York

“The patients I see with type 1 diabetes experience severe DKA and near death. Some end up with a permanent disability. My patients with type 2 diabetes get kidney damage from high blood sugars. And I only see children!!!!!”

- Melanie C.
  Colorado

“Patients often have to choose which medication they can afford. Sometimes patients pick and choose from prescribed medication especially during the ‘donut hole.’”

- Joan B.
  Arizona

“I have had patients end up in the hospital and in the ICU with diabetic ketoacidosis because they could not afford their insulin. These hospitalizations are preventable and are a lot more of a financial burden to our healthcare system than the potential cost of providing insulin reliably to patients who cannot live without it.”

- Isabel C.
  Illinois
“Besides high risk of diabetic complications in the long term, patients have to juggle paying their rent and bills and their insulin. Many type 2 patients live with long term poor control because of this. But for a Type 1, they depend on hospitalizations to get emergency insulin supplies.”
- Daniel D. California

“The consequences of rationing insulin that my patients experience includes elevated a1c, DKA, and kidney damage. Some take days off work because they feel miserable, but that means less pay and they are unable to afford next month’s supply.”
- Cory S. Illinois

“Patients have more frequently been admitted to the hospital with DKA, taking up an ICU bed that is needed for COVID-19 patients. Also, uncontrolled diabetes is a risk factor for severe covid complications if they contract the disease. So now they are presenting to the hospital, potentially exposing themselves to covid cases, and having to 'compete' for the same ICU bed as a COVID patient.”
- Sandra S. Pennsylvania

“My patient is a fifty-seven-year-old who underwent a below-the-knee amputation due to being on disability as her main income. Her monthly disability is only $50 more than her rent. She is on patient assistance now but went for years with over-the-counter insulin and inadequate dosing/control.”
- Jennifer G. Georgia

“We have had patients go into ketoacidosis for rationing insulin. Or had patients develop no healing wounds due to poor glucose control.”
- Sonali T. Texas

“My patients have experienced complications from diabetes such as retinopathy causing vision loss, renal failure, amputation due to chronic hyperglycemia, DKA, multiple hospital/ED admissions due to recurrent infections, poor wound healing and many many more health issues.”
- Krishmita S. Alabama
“My patients have had pre-eclampsia and neonatal complications from inability to get adequate insulin supply for refractory gestational diabetes.”

- Babette G.
- Maryland

“The patients I have that have to ration their insulin due to cost experience poor diabetes control with its associated acute and chronic complications. They also have increased anxiety and depression associated with inadequate resources to buy insulin and associated deterioration of health.”

- Marie C.
- Utah