



TIM JEAN/Staff photos

Nicole Johnson pushes her daughter Jenna, 23 months old, as her other two children Charlie, 6, and Alana, 4, follow a path while they play outside their home in North Andover. Following the death of her husband Charles "Chuck" Johnson from ALS in April 2025 Nicole has been a strong voice and advocacy for families going through a similar journey, grief and joy.

A year without Chuck

A wife finds purpose in advocacy, living life

By Angelina Berube

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NORTH ANDOVER — North Andover mother of three Nicole Johnson is no stranger to the world around her changing at a drastic and life-altering pace.

A year after her husband's death, Johnson is finding her footing with a young family and turning heartbreak into healing for others.

The Eagle-Tribune met Nicole and her husband Charles "Chuck" Johnson on April 11, 2025, to bring awareness to the local family adapting to life with amyotrophic lateral sclerosis (ALS).

The progressive neurodegenerative disease affects



Alana Johnson, 4, touches the ducklings on the back of her father's headstone Charles "Chuck" Johnson who died from ALS in April 2025. The Johnson family can see their home just a short walk away from Ridgewood Cemetery.

nerve cells in the brain and spinal cord, causing muscle weakness that leads to the afflicted person's inability to

move, eat, speak and breathe over time.

Chuck Johnson was diagnosed with ALS on

Valentine's Day in 2024. He lost his battle to the progressive, terminal disease on April 17, 2025, at the age of 39.

"There's no cure for ALS, there's nothing so you're living with that uncertainty and becoming a medical professional in your house," she said about the rapid progression of her husband's disease. "I was basically running a little (intensive care unit) ICU."

"We went through a lot of change in a short period of time," she added. "For me, it's really important to show what life is like afterwards."

A year later, Nicole Johnson, 39, gets hit daily with every stage of grief since

SEE ADVOCACY, PAGE A5



NEW ENGLAND AQUARIUM/Contributed photo
Atlantic right whale Millipede with her calf in
Bay on April 9.

Right whales herded off coast

men asked
gear

Staff

North Atlantic
le calving season
to a close, a pod of
of the endangered
are staying off the
oucester, prompt-
tate Division of
sheries to call on
en to remove the
area waters.

ales are among the
ing six 6 mother/
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ans off Gloucester
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Ann coast, Tillies
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edge. (See the lat-
whale sighting at
org.)

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lobster gear exist
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Area trap/pot clo-
o open May 15.

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and socializing in
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their gear as soon
e and keep away
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at the whales have
the agency said in

he whales are at a
al risk of vessel
AAA Fisheries has
series of volun-
zones off the coast
ay 6, and requests
ers reduce their
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arnings come had
orth Atlantic right
come to a close to
highest number of
orded since 2009,
to scientists at the
and Aquarium.

ual calving sea-
the southeast-
ed States, which
n mid-November
April, produced
r-calf pairs, the
ghest count ever.
ive news for the
endangered spe-
an estimated pop-
about 380.

re three first-time
this season: Cal-
k, Mirror, and May
right whale. Two
as are just 10 years

calves each — just one calf
shy of the current calving
record.

“While a healthy right
whale can give birth every
three to four years, we had
been seeing nearly 10 years
between calves for some
females. Many of this year’s
moms have had shorter inter-
vals—18 of them previously
gave birth within the last six
years—giving us hope that
they may be healthier and
can help grow the population
faster,” said Amy Warren,
scientific program officer in
the aquarium’s Anderson
Cabot Center.

“This year’s multi-gen-
erational cohort is a great
example of the breadth of
the information in the North
Atlantic Right Whale Cata-
log. Mantis and her adult
daughter, Squilla are both
moms this year. Bocce and
Millipede are sisters, and
their aunt, Slalom is also a
mom this year. We have other
aunt-niece pairs and even a
great aunt. These extensive
family trees and life histories
would not be possible with-
out the contributions of the
broader right whale research
community.”

In collaboration with a
network of individuals and
research organizations along
the eastern seaboard, Ander-
son Cabot Center scientists
curate the North Atlantic
Right Whale Catalog, an
extensive photo-identifica-
tion database that allows
them to track right whales’
life stories including births,
injuries, migration pat-
terns, and age to create
detailed histories of each
individual whale. Scientists
use this information to cre-
ate a detailed list of mom-
calf pairs with biographical
information each calving
season. This season’s list is
available on the aquarium’s
website (www.neaq.org/)

Right whales migrate
along the East Coast because
they give birth off Florida
and Georgia and feed off
New England and Canada.
The journey has become
increasingly perilous as
waters have warmed because
their food availability has
changed and that has caused
them to stray from protected
areas of ocean, scientists
have said.

Right whales’ population
fell about 25% from 2010 to
2020. It has ticked up slightly
since then, but the animals
are still in danger of extinc-
tion, conservationists have said.

» Advocacy

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Chuck’s death while raising
three children under 6. She
has days where she feels she
can handle what’s thrown
at her and others where
she’s questioning what’s
happened.

But keeping Chuck’s
memory and legacy alive
through simply living life
with her children is what
she strives to do. Sharing
her story on social media
has kept her going while
continuing to advocate to
find a cure for ALS.

She’s returned to work at
Biogen in Cambridge, Mas-
sachusetts, where her pro-
fessional life intersects with
her personal experience.
She hopes the biotechnology
company, which is exploring
ALS therapies in the pipe-
line, will utilize her insights.

Johnson is also actively
involved in the ALS commu-
nity where she volunteers
with the Pete Frates Foun-
dation and speaks with fam-
ilies on a similar journey.

“It helps my healing and
having a purpose brings
me closer to Chuck,” Nicole
said.

Learning process

Johnson’s children keep
her on her toes as she tries
to capture their evolving
questions about their father
as time passes. The three
young ones have different
memories of him and how
they processed his death.

She recalled the adult-like
reaction and wailing from
her daughter Alana, now
4, who understood what it
meant at the hospital last
April when she was told her
father would not come back
home with them. Alana
wailed.

There’s now open conver-
sations about death around
the house as the kids first
experience with death was
of their father’s. Her son
Charlie has fears of his
mother dying.

“It’s trying to reassure
him that I’m doing the best
to take care of my body
and there’s so many peo-
ple around to take care of
them,” Nicole said.

She also understands her
2-year-old daughter Jenna’s
grief journey will come later
as she was only an infant
when her father died and
will rely on photos and vid-
eos to remember him.

The family never planned
too far in advance. Nicole
holds onto memories of trav-
eling in Chuck’s modified
van together, the kids riding
on his wheelchair and hang-
ing out in bed with him.

“It’s even just the memo-
ries of Jenna laying on him,”
Nicole said.

It was always about “mak-
ing it work” where Chuck
was able to spend quality
time with his children. On
his last day before his med-
ical emergency, the family
was outside in the backyard
enjoying a beautiful, sunny
afternoon.

In the immediate after-
math of Chuck’s death,



TIM JEAN/Staff photo

Nicole Johnson with her three children Jenna, 23 months
old, Alana, 4, and Charlie, 6, play outside their home in
North Andover.



Nicole Johnson with her three children Jenna, 23 months
old, Alana, 4, and Charlie, 6, visit the grave of Charles
“Chuck” Johnson who died from ALS in April 2025.



Nicole Johnson and her daughter Jenna, 23 months old,
play a game while watching her other two children play
outside their home in North Andover.

Nicole said she felt guilty
for not doing enough. She
still kicks herself for not
videotaping more in the
beginning.

For her family, they
slowly parted ways with the
equipment and objects that
became symbolic of Chuck’s
ALS and care.

His wheelchair and
shower chair were no lon-
ger needed. The 121-foot
ramp in the backyard was
tacked down and the family’s
modified van all left their
home within six weeks of
his death.

“Can you help us move
this stuff down to the
garage? It’s going to a new
family,” Nicole recalled
asking her kids. She said
her children handled the

The gravestone now has
photos of the “chucklings”
and a scene from Ipswich
where they would vacation,
all imagery comforting to
the three children.

“They call it daddy’s spe-
cial stone,” Nicole said.

New generation

There was joy in another
year of change for the young
family though.

Nicole has cherished time
with her kids and sees her
husband in each other from
the way Charlie throws a
ball to Jenna’s facial expres-
sions. Music played a role
in their lives before his ALS
diagnosis and continues to
do so with concerts lined up
to see some of their favorite
country musicians.

Their loved one’s mem-
ory was honored at three
weddings last year and the
family has since traveled to
Florida.

The kids ask about going
back weekly, Nicole said.

“It showed us we can
travel with three kids, we
can do it,” she said.

Her husband loved boat-
ing and wanted his own
boat. The family got out on
the lake in Ipswich and Lake
George last summer.

Her son Charlie showed
his father’s excitement about
the water.

“He’s going to learn how
to drive a boat pretty soon,”
Nicole said with a laugh.
“Charlie will be the new
generation out there.”

She’s learned to find grace
this year, for herself, her
support system and Chuck’s
memory.

Nicole empathized with
Chuck wanting to be there
for his children, participat-
ing in activities with them
even though he couldn’t
move and had no control
over anything.

“He could have stayed in
bed all day, but he didn’t,”
she said. “We were in the
thick of it in terms of active
caregiving and planning and
parenting logistics.”

Nicole has been able to
look back on the early days
of Chuck’s diagnosis with
more clarity and give her-
self credit for establishing
her support team. As she’s
talked with other ALS fam-
ilies, she has realized how
lucky she was to have a
support network of family
members and caregivers.

She’s also found empa-
thy toward family mem-
bers, recognizing grief will
live with them all in differ-
ent ways.

And with herself, Nicole
said she knows her needs
evolve every few months.
She’s going to Portugal for
work and it will be a few
days without her kids. It
will be a lesson for them,
she explained that their
mother can leave, come
back, work and that mom
has a life.

Johnson’s family is still
transitioning from having
grandparents take shifts
sleeping over, but half the
time it’s just her and the
children.

“We’ll get to the point
where it’s just us all the time.”

» Book

6-years-old, and who old

said. “We knew we wanted

his muscles at a slower pace,