

STAGE: EARLY (0-10 YO)

SOURCE OF PAIN	POSSIBLE CAUSES	Diagnosis and/or POSSIBLE TREATMENT
Musculoskeletal (cramping, aching)	Shortening tendons (legs, feet), toe walking	<ul style="list-style-type: none"> Treatment: Heat, massage, analgesics (Tylenol), stretching, braces (AFO's)
Musculoskeletal (aching)	Hypokalemia (low potassium – very rare)	<ul style="list-style-type: none"> Diagnosis: evaluation of serum potassium Treatment: supplementation as needed
Musculoskeletal (aching)	Vitamin D deficiency	<ul style="list-style-type: none"> Diagnosis: blood tests (25 OH vitamin D level) Treatment: dietary evaluation and supplement vitamin D as needed
Leg/foot	Poorly fitting orthoses/braces (AFO's, KAFO's)	<ul style="list-style-type: none"> Diagnosis and treatment: evaluation by orthotist to check fit; offer analgesic medications as needed
Abdomen	Gastroesophageal reflux (GERD, "heartburn")	<ul style="list-style-type: none"> Treatment: Avoid NSAID's (aspirin, ibuprofen, naproxen); antacids/proton pump inhibitors (PPI's) may help
Abdomen	Constipation	<ul style="list-style-type: none"> Treatment: Increase fruit, fiber in diet; ensure adequate hydration; medications: laxatives, stool softeners
Abdomen	Hypercalcemia (calcium level is too high – very rare)	<ul style="list-style-type: none"> Diagnosis: Evaluation of serum calcium level Treatment: evaluation of calcium in diet/supplements; adjust as needed
Headache	If worse in am, consider obstructive sleep apnea or nocturnal hypoventilation (ineffective breathing during sleep)	<ul style="list-style-type: none"> Diagnosis: careful history, sleep study to evaluate for obstructive sleep apnea and/or nocturnal hypoventilation Treatment: assistive ventilatory assistance as needed (C-PAP if obstructive sleep apnea is diagnosed; BiPAP or VPAP for nocturnal hypoventilation)

STAGE: TWEENS AND TEENS (11-17 YO)

SOURCE OF PAIN	POSSIBLE CAUSES	Diagnosis and/or POSSIBLE TREATMENT
Musculoskeletal Back and hip pain (aching)	Poor posture, uncomfortable positioning/pressure	<ul style="list-style-type: none"> Treatment: Change position/pressure frequently; equipment evaluation for changes needed in positioning/pressure; offer analgesic medications as needed
Back pain (NO history of trauma)	Compression fractures	<ul style="list-style-type: none"> Diagnosis: X-ray to determine the presence of fractures, evaluation for osteoporosis Treatment: evaluation for osteoporosis; management of osteoporosis; offer analgesic medications as needed
Back pain (chronic)	Scoliosis	<ul style="list-style-type: none"> Diagnosis: X-ray to determine the presence of scoliosis Treatment: continuous evaluation and management by orthopedics; surgical correction as indicated; offer analgesic medications as needed
Musculoskeletal (aching)	Hypokalemia (low potassium – very rare)	<ul style="list-style-type: none"> Diagnosis: Evaluation of serum potassium Treatment: supplementation as needed
Musculoskeletal (aching)	Vitamin D deficiency	<ul style="list-style-type: none"> Treatment: Assure adequate intake of Vitamin D and calcium; evaluation of 25 OH Vitamin D level; supplementation as needed
Chest pain	Musculoskeletal pain	<ul style="list-style-type: none"> Diagnosis: moderate to severe pain, worsens with movement, breathing, coughing; gets better and worse Treatment: Warmth, rest; analgesic medicine as needed
Chest pain	Cardiac	<ul style="list-style-type: none"> Diagnosis: severe chest pain, constant and consistent (does not get better or worse, not effected by movement or breathing) Treatment: call cardiologist; go to emergency room
Limb pain (history of trauma)	Long bone fracture	<ul style="list-style-type: none"> Diagnosis: X-ray to determine presence of fracture; continuous evaluation for presence of fat embolism Treatment: management of fracture
Limb pain	Joint contracture pain	<ul style="list-style-type: none"> Treatment: Evaluate positioning, musculoskeletal support; analgesic medications as needed
Leg/foot pain	Poorly fitting orthoses/braces (AFO's, KAFO's)	<ul style="list-style-type: none"> Diagnosis and treatment: evaluation by orthotist to check fit; offer analgesic medications as needed

Parent Project Muscular Dystrophy

Abdominal pain

Kidney stones (small hard deposits of mineral and acid salts in the kidney)

- Diagnosis: Presentation may include: severe side and back pain below the ribs, spreads to abdomen/groin and comes in waves; pain with urination, discolored urine (pink, red, brown), nausea/vomiting, constant and/or frequent urge to urinate, possible chills and fever; symptoms may change as stone moves; constipation; Blood tests (check for level of calcium or uric acid in blood); urine tests (24 hour urine collection to look for stone-forming minerals), Imaging (X-ray, CAT scan with or without dye), evaluation of stones that may have already passed.
- Treatment: increased hydration, ultrasound to break up the stone, surgical or endoscopic removal of the stone. Medications may include: analgesics, alpha blockers (relax the ureter so that the stone may pass more easily). Parathyroid gland surgery: too much parathyroid hormone can increase calcium levels and cause stone formation.

Abdominal pain

Cardiac disease/heart failure (In advanced heart failure, the heart is not able to adequately pump the blood forward, so there can be an accumulation of fluid and blood in the liver and gut; this can cause a loss of appetite, abdominal edema, fullness or bloating, nausea, and/or vomiting)

- Diagnosis: cardiac MRI, cardiac ultrasound, blood tests.
- Treatment: Medications may include: diuretics (to decrease the volume of blood that the heart needs to pump), medications to help the heart pump more effectively (milrinone); mechanical devices (ventricular assist devices or ICD, implantable cardioverter defibrillator or ICD) or heart transplant may be discussed.

Abdominal pain

Constipation

- Treatment: Increase fruit, fiber in diet; ensure adequate hydration; medications: laxatives, stool softeners

Headache

If worse in am, consider nocturnal hypoventilation (ineffective breathing during sleep)

- Diagnosis: careful history, sleep study to evaluate for nocturnal hypoventilation
- Treatment: assistive ventilatory assistance as needed (BiPAP or VPAP for nocturnal hypoventilation)

STAGE: ADULTS (18 +)

SOURCE OF PAIN	POSSIBLE CAUSES	Diagnosis and/or POSSIBLE TREATMENT
Musculoskeletal Back, Hip	Pain/pressure	<ul style="list-style-type: none"> Treatment: Change position/pressure frequently; equipment evaluation; medication as needed
Skin	Pain/pressure	<ul style="list-style-type: none"> Treatment: Evaluate for pressure ulcer; medical management as needed
General muscle pain, cramping	Hypokalemia (low potassium – very rare)	<ul style="list-style-type: none"> Diagnosis: Evaluation of serum potassium Treatment: supplementation as needed
Chronic musculoskeletal pain	Vitamin D deficiency	<ul style="list-style-type: none"> Treatment: Assure adequate intake of Vitamin D and calcium; evaluation of 25 OH Vitamin D level; supplementation as needed
Chest pain	Hypomagnesemia (low magnesium – very rare)	<ul style="list-style-type: none"> Diagnosis: Evaluate serum magnesium levels Treatment: supplement as needed
Chest pain	Pneumothorax (Severe stabbing chest pain, worse with inspiration, shortness of breath) (“collapsed lung” caused by air leaking into the space between the lung and chest wall causing parts of the lung to collapse)	<ul style="list-style-type: none"> Diagnosis: X-ray, CT scan Treatment: monitoring (if mild), removal of the air with a needle or chest tube, surgical repair of the leak
Chest pain	Cardiac	<ul style="list-style-type: none"> Diagnosis: severe chest pain, constant and consistent (does not get better or worse, not effected by movement or breathing) Treatment: call cardiologist; go to emergency room
Abdominal pain	Esophagitis (painful, difficult swallowing, chest pain)	<ul style="list-style-type: none"> Diagnosis: upper endoscopy (a small tube is inserted into the esophagus and stomach to look at the tissue) or an upper GI/ barium swallow (to look at the location and extent of esophageal damage) Treatment: depends on the cause; medications may include: analgesics, antacids, proton pump inhibitors (PPI’s); dietary management
Abdominal pain	Gastritis (chronic or acute pain)	<ul style="list-style-type: none"> Diagnosis: upper endoscopy (see above), blood test (to check for anemia (low red blood cell count), fecal (stool) blood test Treatment: depends on the cause; medications may include: antacids, PPI’s, antibiotics, dietary management, vitamin B12 (if needed)

Parent Project Muscular Dystrophy

Abdominal pain

Peptic ulcer disease (burning pain in the middle or upper stomach, worst between meals or at night), burning abdominal pain, nausea and/or vomiting; if severe, stool may be black or look like “coffee grounds;” vomiting blood (“coffee grounds”), weight loss, severe mid-upper abdominal pain

- Diagnosis: upper endoscopy (see above), blood test (to check for anemia (low red blood cell count), fecal (stool) blood test
- Treatment: depends on the cause; may require endoscopic or surgical repair; medications may include PPI’s, antibiotics

Abdominal pain

Gall stones (hardened deposits of digestive fluid that form in the gall bladder; sudden intense, worsening pain in the upper right or center abdomen, back pain between shoulder blades, right shoulder pain

- Diagnosis: includes blood tests, ultrasound or CAT scan; HIDA scan (shows whether the gallbladder is functioning properly), endoscopic evaluation (ultrasound or retrograde cholangiopancreatography (ERCP)(can diagnose and remove gallstones)
- Treatment: usually surgical or endoscopic removal of the gallbladder

Abdominal pain

Kidney stones (small hard deposits of mineral and acid salts in the kidney; severe side and back pain below the ribs, spreads to abdomen/groin and comes in waves; pain with urination, discolored urine (pink, red, brown), nausea/vomiting, constant and/or frequent urge to urinate, possible chills and fever; symptoms may change as stone moves)

- Diagnosis: blood tests (check for level of calcium or uric acid in blood); urine tests (24 hour urine collection to look for stone-forming minerals), Imaging (X-ray, CAT scan with or without dye), evaluation of stones that may have already passed.
- Treatment: increased hydration, ultrasound to break up the stone, surgical or endoscopic removal of the stone. Medications may include: analgesics, alpha blockers (relax the ureter so that the stone may pass more easily). Parathyroid gland surgery: too much parathyroid hormone can increase calcium levels and cause stone formation.

Abdominal pain

Cardiac disease/heart failure (In advanced heart failure, the heart is not able to adequately pump the blood forward, so there can be an accumulation of fluid and blood in the liver and gut; this can cause a loss of appetite, abdominal edema, fullness or bloating, nausea, and/or vomiting)

- Diagnosis: cardiac MRI, cardiac ultrasound, blood tests.
- Treatment: Medications may include: diuretics (to decrease the volume of blood that the heart needs to pump), medications to help the heart pump more effectively (milrinone); mechanical devices (ventricular assist devices or ICD, implantable cardioverter defibrillator or ICD) or heart transplant may be discussed.

Parent Project Muscular Dystrophy

Back pain (NO history of trauma)	Compression fractures	<ul style="list-style-type: none">• Diagnosis: X-ray to determine the presence of fractures; evaluation for osteoporosis• Treatment: analgesics, management of osteoporosis
Back pain (chronic)	Scoliosis	<ul style="list-style-type: none">• Diagnosis: X-ray to determine the presence of scoliosis• Treatment: continuous evaluation and management by orthopedics; surgical correction as indicated
Limb pain (history of trauma)	Long bone fracture	<ul style="list-style-type: none">• Diagnosis: X-ray to determine presence of fracture; management of fracture• Treatment: surgical correction and orthopedic management, continuous evaluation for presence of fat embolism
Limb pain	Joint contracture pain	<ul style="list-style-type: none">• Treatment: Evaluate positioning, musculoskeletal support; analgesic medications as needed
Headache	If worse in am, consider nocturnal hypoventilation (ineffective breathing during sleep)	<ul style="list-style-type: none">• Diagnosis: careful history, sleep study to evaluate for nocturnal hypoventilation• Treatment: assistive ventilatory assistance as needed (BiPAP or VPAP for nocturnal hypoventilation)

Important information to know about your/your child/s pain:

Onset

Do you have pain? If so, when did the pain start?

Location

Where on your body does the pain feel worst?

Duration/frequency

Is this new pain or pain that you have had before?

Is the pain constant or does it come and go?

If it comes and goes, how often does it come?

If it comes and goes, how long does it last when it comes?

Severity

On a scale of 1-10, with a #1 being no pain and #10 being the worst pain you have ever had, what number would you rate your pain?

Setting

Where were you/what were you doing when your pain started?

Aggravating or Relieving factors

What causes your pain to get worse? What causes your pain to get better?

Associated Manifestations

Are you experiencing any other symptoms? (i.e., headache, dizziness, nausea, etc.)

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